

Family Support 360  
People Leading Accessible Networks of Support (PLANS)

2008 Evaluation Report

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## Introduction

The mission of the Family Support 360 PLANS Project at the time of the evaluation was to empower people to achieve their dreams through choice of services and supports.

In partial fulfillment of this mission, PLANS leaders began the evaluation process as soon as the project was funded. This report contains the latest evaluation information.

Persons reading this document will find duplication of information. This was done intentionally to allow for ease in studying all or part of the results and findings and to allow readers to draw their own conclusions from the data. Each section can be viewed as independent of the other sections. The table of contents is detailed to allow readers to find and study the section that they find most helpful. The evaluator's intent for the report is to find the balance between brief enough to be useful and so detailed that it gathers dust on a shelf.

The report includes a description of the PLANS Project, the rationale for evaluation, the methodology used, the results, and recommendations for further study and evaluation.

Stake holders are encouraged to examine the data on their own and in small groups. Powerful possible discussion questions include 1). What observations can we make about this data? 2). What important points seem to "pop out"? 3). What are some patterns or trends that are emerging? 4). What seems to be surprising or unexpected? and 5). What are some things we have not explored?

## Description of PLANS Project

The PLANS project is best described by its mission statement, goals, and history.

### *Mission*

As stated earlier, the mission of the Family Support 360 PLANS Project is to empower people to achieve their dreams through choice of services and supports.

### *Goals*

The goals of the project are to 1). Help people make their own choices, 2.) Help people live and work in their community, and 3). Help people find the supports that they want in their community. The evaluation information is organized according to these three goals.

### *Short History*

According to the government developmental disabilities website, <http://dhs.sd.gov/dd/plansindex.aspx>, the PLANS 360 Project would do “whatever it takes to give people the ability to get the services they need” to live as independently as possible. The PLANS 360 Project was realized as a result of a grant award in 2004.

South Dakota was one of the twenty-one states to which the U.S. Department of Health and Human Services awarded priority grants in 2004. The South Dakota grant, "Family Support 360 People Leading Accessible Networks of Support (PLANS)," began in the state as a pilot project. A plan to deliver comprehensive services through a single coordinator to persons with disabilities, family representatives, and agencies who provide the services and supports was developed. The first coordinator was hired in southeastern South Dakota to travel to the families to provide planning for the services and supports. Later three more coordinators were added to serve other regions of the state and in the fall of 2008, a fifth coordinator was hired to serve the

central region. The data was collected for the 2008 evaluation before the fifth coordinator was hired. See map in Appendix A for regions served in the state at the time of data collection.

The focus of the Family Support 360 PLANS Project offers participants choice, individualized services, independence, satisfaction, self-determination, inclusion, self-advocacy, cultural sensitivity, and flexibility.

The grant will officially end in September of 2009 and the project will continue to be funded through a Medicaid waiver.

### *Background of Previous Evaluation*

Evaluation of the project began almost immediately with data collection in 2003 and 2004 with the target population. These surveys and evaluation were conducted by the South Dakota Division of Developmental Disabilities.

## Rationale for Evaluation

The ultimate goal of the evaluation was to identify ways to better serve people with developmental disabilities and their families. The current evaluation was elicited to further ascertain the quality of services provided to participants, to assess participant satisfaction, and to improve practices.

## Methodology

The evaluation follows the traditional model of research recognized by the American Association of Psychological Studies. The survey instrument used for the 2008 evaluation was based on the previous surveys conducted in 2003 and 2004. Area coordinators obtained the consumer's consent to be interviewed. See Appendix B for PreSurvey form.

Selected response answers, otherwise known as multiple choice answers, were elicited regarding where consumers live, where they work, their friends and family, and service providers. Interviewees were also encouraged to provide additional comments to each of the questions and/or sections.

## *Data Sources*

Data sources included a random sample of twenty-three male and seventeen female PLANS participants ranging in age from 18-70. Care was taken to obtain representative numbers of males and females, and age groups in each of the geographic areas. The number of interviewees is not statistically significant, nor is any aggregate group of respondents large enough to be statistically significant.

Data was collected via interview questions with participants in the PLANS 360 Project. See Appendix B for complete interview questionnaire. All interviews were conducted by a single interviewer from outside of the Department of Human Services. The interviewer determined that over ninety percent of the respondents answered the questions independently or with little assistance. She also determined that over eighty percent of the respondents answered the questions in a consistent manner. The interviewer recognized that some respondents may have answered in a manner in which they thought was expected.

### *Evaluator*

Technology and Innovations in Education staff member Marilyn Hofer, an external evaluator who has experience in data collection and analysis, organizational development, communication, and evaluation including action research, was hired to conduct the interviews, report the results, analyze the findings, and make recommendations for further study.

### *Analysis*

Survey results were analyzed to determine both current consumer perception and change in consumer perception over time.



## Results

Results were reported by individual question results, and were also compared to the responses to the same questions asked by the South Dakota Division of Developmental Disabilities in the two previous surveys completed in 2003 and 2004. See Appendix C for charts showing results and comparisons. Appendix C is an overview of all of the interview responses and would be a resource for readers to use as a basis for examining the data individually or in small teams. The discussion questions suggested in the introduction could be used to further explore the information and draw conclusions. If readers wish to compare the answers over time, it should be noted that although the percentages can be compared, the number of interviewees changed from 20 in 2003 to 33 in 2004 to 40 in 2008.

Results are also reported by groups of questions based on the three goals of the PLANS Project and a group of questions targeting general satisfaction of participants. See Goals section for further discussion of these results.

### *Demographics*

As noted earlier, interviewees were randomly selected within demographic groups to be representative of South Dakota PLANS participants. Eleven respondents fell into the transition age category of 18-22; eleven respondents were 23-35 years of age, eleven respondents were 37-49, and seven respondents were 52-70. One third to one half of the participants in each of the four areas of the state at the time of the interviews were interviewed. See Appendix I for demographic information.

### *Goals*

In the analysis, results were grouped according to the three goals of the project: 1). Help people make their own choices, 2.) Help people live and work in their community, and 3). Help

people find the supports that they want in their community. The evaluation information is organized according to these three goals.

Seventeen questions were targeted toward goal one, help people make their own choices. The overall results of these questions indicate that on average 53% of all interviewees in all questions in this target group felt they make their own choices. Answers ranged from a high of 87.5 % to a low of 7.5% affirmative replies. Over 87% of interviewees answered their own questions, which indicates making their own choices. In response to question 45, over 82% of interviewees indicated that they decide how they spend their free time. Other areas in which respondents felt they had a great deal of choice were using the phone, setting their schedule, and seeing their friends. The lowest affirmative response, 7.5%, was when answering if they chose who helps them at work. See Appendix D for complete results of goal one questions.

Sixteen questions were targeted toward goal two, help people live and work in their community. The overall results of these questions indicate that on average 65% of all interviewees in all questions in this target group saw themselves as part of a community. Answers ranged from a high of 91 % to a low of 27% affirmative replies. Responses to question 33 indicate that 91% of interviewees indicated that they go out on errands or appointments. Respondents also reported to a high degree that they go shopping, out to eat, and out for entertainment. The lowest affirmative response, 27.5%, was when answering if they go to clubs or other community meetings. See Appendix E for complete results of goal two questions.

Eleven questions were targeted to goal three, help people find the supports that they want in their community. The overall results of these questions indicate that on average 55% of all interviewees in all questions in this target group see themselves as having support or help at work or at home. Results also indicated that respondents know their coordinator and receive help

from the coordinator. Answers ranged from a high of 90 % to a low of 10% affirmative replies. Responses to question 19 indicate that 90% of interviewees indicated that they know their coordinator. Respondents also reported to a high degree that their coordinator asks them what they want and need and helps them make a plan to get what they want and need. The lowest affirmative response, 10%, was when answering if they know how much money is spent on their providers. See Appendix F for complete results of goal three questions.

Nine questions were targeted to ascertain general satisfaction. The overall results of these questions indicate that on average 70% of all interviewees in all questions in this target group saw themselves as happy and satisfied with the services they receive. Answers ranged from a high of 93 % to a low of 43% affirmative replies. Responses to question 25 indicate that 93% of interviewees indicated that they are happy with the services they receive from the coordinator. Respondents also reported to a high degree that they are happy with their home, their personal life, and felt happy the day of the interview. The lowest affirmative response, 43%, was in answer to question 10, if they receive help meeting independent living goals. See Appendix G for complete results of general satisfaction questions.

Interviewees were also invited to make comments regarding the questions and after each section of questions. The comments were in the areas of additional services needed, changes to services, and information that the participant wished to have included in the report. Respondent comments can be found in Appendix H.

### *Comparison to Previous Interview Question Results*

The questions asked in 2008 were based on the questions asked in 2003 and 2004. These questions seem to be loosely based on the National Core Indicators developed by a collaboration of the National Association of State Directors of Developmental Disabilities Services and

Human Services Research Institute in 2002. Find more information on these indicators at  
<http://dhs.sd.gov/dd/division/ncIReports.aspx>

## Implications/Recommendations

As noted earlier, the ultimate goal of the evaluation was to identify ways to better serve people with developmental disabilities and their families. The current evaluation was elicited to further ascertain the quality of services provided to participants, to assess participant satisfaction, and to improve practices.

In order to continue to improve practice and the satisfaction of PLANS consumers, four specific recommendations might be considered.

1. Acquiring information from family members or guardians could also inform PLANS leaders of the satisfaction of participants. The information from this viewpoint may also give stakeholders information regarding what practices to continue or how current practices could be improved.

2. Further evaluation could be more closely aligned with the national core indicators. According to the government website, <http://dhs.sd.gov/dd/division/ncIReports.aspx>, South Dakota has been involved in creating these indicators. Aligning the survey more closely with these indicators would inform practices and heighten the consistency of evaluation.

3. Consistent language and terminology could insure that the results of the interviews are consistent across state areas. For instance, the interviewer found that in some coordinator areas, interviewees were familiar with the terms coordinator, payee, companion care, and annual meeting. In other coordinator areas, consumers refer to any of these supports as helpers and meetings. It was also noticed that coordinators refer to the PLANS participants in different terms. Consumers, clients, participants, and people are all used. A discussion of what terms to use throughout all areas would elevate the consistency of evaluation results and other reports.

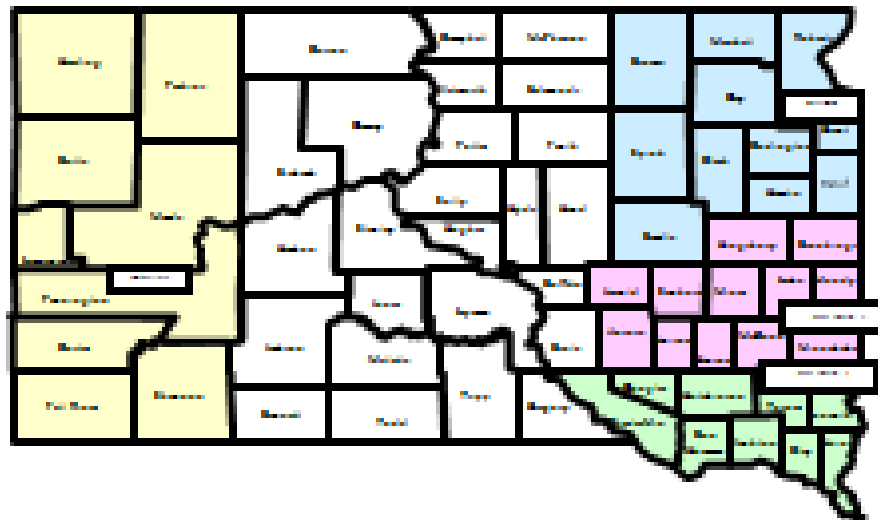
4. Comments from participants could inform content of next surveys and perhaps new practices. Individual comments reflect four themes: 1). Interviewees who made comments emphasized that they appreciate their coordinators and the PLANS Project and they are receiving good help. 2), Comments reveal that participants think it is important to be independent. 3.) Comment makers perceive that more help is needed in the area of employment. 4.) Comment makers perceive that more help is needed in the area of transportation.

Although questions were asked in the survey about each of these themes, it is interesting to note that more than one interviewee emphasized each of these areas.

## Summary

The evaluation report shows that the PLANS Project is on track to help people make their own choices, live and work in their communities, and help participants find supports. The results of the data indicate what practices participants are satisfied with and should be continued as well as some ideas for additional practices to employ in helping PLANS participants achieve their dreams through supports and services.

Appendix A  
Map of areas served in PLANS Project at the time of data collection





Appendix B  
2008 Survey

## Pre-Survey information

This form should be completed by the Family Support 360 PLANS Coordinators using appropriate information sources, such as the Consumer Empowerment Services database. The interviewer will use this information to schedule and conduct the interview.

Name of person completing this form: \_\_\_\_\_

Date: \_\_\_\_\_

Participant's Name: \_\_\_\_\_

Gender: \_\_\_\_ Male \_\_\_\_ Female

Phone: \_\_\_\_\_ - \_\_\_\_\_

Home address: \_\_\_\_\_  
Street

\_\_\_\_\_  
City State Zip

*If applicable, please answer the following:*

Is the signature of a legal guardian required for this participant to consent to participation in this survey? \_\_\_\_ Yes \_\_\_\_ No

Name of Guardian: \_\_\_\_\_

Phone: \_\_\_\_\_ - \_\_\_\_\_

Home address: \_\_\_\_\_  
Street

\_\_\_\_\_  
City State Zip

E-mail address: \_\_\_\_\_

Did participant/guardian give verbal consent for interviewer to contact him/her?

\_\_\_\_ Yes \_\_\_\_ No

Did participant/guardian give written consent to be interviewed?

\_\_\_\_ Yes \_\_\_\_ No

Please attach copy of consent form.

## Contact Information

Who should the interviewer call to arrange an interview with this person?

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Daytime Phone: \_\_\_\_\_ Evening Phone: \_\_\_\_\_

Cellular Phone: \_\_\_\_\_ E-mail address: \_\_\_\_\_

**We would like to talk with people alone, when appropriate. Some people may feel uncomfortable with strangers, may have community protection issues, or may have medical or behavioral issues that require someone else to be present during the interview**

Do you recommend that a caregiver be present while this person is interviewed?

\_\_\_ Yes \_\_\_ No

Does this person have any special communication needs? (Example: primary language other than English, sign language, communication board.) Please explain what arrangements are needed for the interview.

\_\_\_\_\_  
\_\_\_\_\_

What is the name and phone number of this person's coordinator?

Name: \_\_\_\_\_ Phone: \_\_\_\_\_ / \_\_\_\_\_

Cellular Phone: \_\_\_\_\_

E-mail address: \_\_\_\_\_

If this person has someone who helps represent him/her at planning meetings and in making important decisions, please provide this person's name, phone number, and relationship. (Note: this may include staff, family, friends, or guardians who are involved in the person's life.)

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Please indicate who this person lives with.

\_\_\_ lives alone \_\_\_\_\_ lives with parent/relatives

\_\_\_ lives in shared house or apartment \_\_\_ lives with spouse

If applicable, please indicate what this person calls his/her job, school or volunteer work.

Place of work: \_\_\_\_\_

School: \_\_\_\_\_ Volunteer work: \_\_\_\_\_

## **Personal Information**

Date of birth: (mm/dd/yy) \_\_\_ / \_\_\_ / \_\_\_

Age: \_\_\_\_\_

Gender: \_\_\_ male \_\_\_ female

What is this person's race? (check ONE)

\_\_\_ American Indian or Alaska Native

☐ Asian  
☐ Black or African American  
☐ Native Hawaiian or Other Pacific Islander  
☐ White  
☐ Other race not listed  
☐ Two or more races  
☐ Don't know

Is this person Hispanic or Latino?

☐ No  
☐ Yes  
☐ Don't know

Legal status: (check one)

☐ Legally competent adult  
☐ Guardian or conservator (including parent, relative, or non-relative) has been assigned  
☐ State guardian or conservator has been assigned  
☐ Don't know

Does this person have a payee or someone else who manages his/her money?

☐ No  
☐ Yes  
☐ Don't know

Marital status: (check one)

☐ Single, never married  
☐ Married  
☐ Single, married in past  
☐ Don't know

How is this person diagnosed in his/her records? (check one)

☐ Does not have MR label  
☐ Mild MR  
☐ Moderate MR  
☐ Severe MR  
☐ Profound MR  
☐ Don't know or unspecified in records

What disabilities other than MR are noted in this person's records? (check all that apply)

☐ Mental illness/psychiatric diagnosis (e.g. depression)  
☐ Autism  
☐ Cerebral Palsy  
☐ Brain injury  
☐ Seizure disorder/neurological problem  
☐ Chemical dependency  
☐ Vision or hearing impairment  
☐ Physical disability  
☐ Communication disorder  
☐ Alzheimer's disease  
☐ Down Syndrome  
☐ Other disabilities not listed  
☐ No disabilities other than MR  
☐ Don't know or unspecified in records

What is this person's primary means of expression? (check one)

☐ Speaks English  
☐ Speaks other primary language

- ☐ Uses gestures
- ☐ Uses sign language or finger spelling
- ☐ Uses communication device
- ☐ Other
- ☐ Don't know

## Living Situation:

How many different places has this person lived within the past year? (Present home counts as one.)

\_\_\_ \_\_\_ Number of places

How would you characterize the place where this person lives? (check one)

- ☐ Independent home or apartment
- ☐ Parent/relative's home
- ☐ Foster care or host home (person lives in home of unrelated, paid caregiver)
- ☐ Other (specify) \_\_\_\_\_
- ☐ Don't know

Who owns or leases the place where this person lives? (check one)

- ☐ Family, guardian, or friend
- ☐ Person rents home (name is on the lease)
- ☐ Person owns home (name is on the title)
- ☐ Don't know
- ☐ Other

What amount of support does this person receive at home? (check one)

- ☐ 24-hour on-site support or supervision (people living with or being available in his/her home during any hours that s/he is home)
- ☐ Daily on-site support (for a limited number of hours/day, not round-the-clock)
- ☐ Less frequent than daily support
- ☐ As needed visitation and phone contact
- ☐ None of the above
- ☐ Don't know

## Other Supports and Services:

What other services and supports does this person currently receive? (check one column for each):

no	yes	don't know	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Service Coordination/Case Management
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vocational – supported employment
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community participation/accessibility connections (companion care)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Personal Care Services
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Special Medical Adaptive Equipment and Supplies

—	—	—	Respite
—	—	—	Vehicle modifications
—	—	—	Enrolled in school system
—	—	—	Other

## Interview with person receiving services and supports:

### General Instructions:

- ✧ This section may only be completed by directly interviewing the person receiving services and supports.
- ✧ Do not use responses from any other person to complete this section.
- ✧ Participants may skip any question. If the person receiving services does not respond to a question or gives an unclear response, code the question as “Don’t know, no response.”
- ✧ Do not leave any questions blank.
- ✧ Be sure to read all instructions carefully.
- ✧ If possible, the interview should be conducted in private. Parents or guardians may be present if they insist. Others may be present if the consumer requests it, or if another person is needed for interpretation purposes. If a private interview may pose risks to the interviewer, then someone else should be present. If others are providing assistance, interviewers should emphasize that we are trying to find out the participant's perspective.
- ✧ Help the person with any words that are not understood. You may repeat or rephrase questions to improve understanding. Some questions have suggested rephrasing in parentheses - you do not need to limit yourself to these suggestions.
- ✧ Prior to the interview, interviewers should use the pre-survey form to fill in the blanks throughout the survey. Using familiar names and terms during the interview will help ensure that the person understands the questions.
- ✧ A wide margin is provided for recording notes as necessary. Please be sure to fill out the Interviewer Feedback Sheet after each interview

Take a few minutes to introduce yourself and make the person feel comfortable. Read or paraphrase the following introduction. Pause after each statement, making sure the respondent understands.

“Hi, my name is \_\_\_\_\_. I’m from \_\_\_\_\_, and I’m here to ask you some questions about where you live, where you work, your friends and family, and the people who help you. By answering these questions, you are helping us figure out how people using the Family Support 360 PLANS Project are doing, and how to make supports and services better.”

"This is not a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer."

"You don't have to answer any questions that you don't want to. Just tell me if you don't want to answer."

"I'd like to know your opinions, how you feel about things. Whatever you tell me will be kept private, so you can be honest."

Ask respondent to sign consent form before proceeding with interview, if you don't already have it

## **WORK and DAYTIME ACTIVITIES**

**For Questions 1-3**, include all types of work and daytime activities - paid, unpaid, community-based jobs, supported employment, volunteer work, etc. If participant has more than one job/day activity, ask how s/he feels in general or "most of the time." If respondent works and attends school, ask about work only.

1. I'd like to start by asking you about what you do during the day – if you have a job or other place that you go to.

Do you work/volunteer at (go to) \_\_\_\_\_?

Do you like working (going) there?

- ☐ **NOT APPLICABLE** – no job or day activity
- ☐ Yes
- ☐ In-between
- ☐ No
- ☐ Don't know, no response, unclear response

2. Do you have someone who helps you at work?

- ☐ **NOT APPLICABLE** – no job or day activity
- ☐ Yes
- ☐ Sometimes
- ☐ No
- ☐ Don't know, no response, unclear response

3. Do you choose (or pick) who helps you at work? (*Did you get to interview them? Could you request someone different?*)

- ☐ **NOT APPLICABLE** - no job or day activity staff
- ☐ Yes

- \_\_\_ Some staff, or staff are assigned but s/he can request someone different
- \_\_\_ No
- \_\_\_ Don't know, no response, unclear response

4. Are you feeling happy or sad today?

This is a consistency check question – do not rephrase.

- \_\_\_ Happy
- \_\_\_ In-between
- \_\_\_ Sad
- \_\_\_ Don't know, no response, unclear response

## Home

Now I'm going to ask you about where you live.

5. Do you like your home or where you live? (*Do you like living here?*)

- \_\_\_ Yes
- \_\_\_ In-between
- \_\_\_ No
- \_\_\_ Don't know, no response, unclear response

6. Can you be alone if you want to? (*Can you have privacy?*)

Here we are looking at privacy (e.g. going in a room and closing the door), not the person's need for supervision (e.g. staying home alone).

- \_\_\_ **NOT APPLICABLE** - lives alone
- \_\_\_ Yes, has enough time alone
- \_\_\_ No, would like more time alone
- \_\_\_ Don't know, no response, unclear response

7. Are you ever afraid or scared when you are at home?

- \_\_\_ [Yes] - most of the time
- \_\_\_ Sometimes
- \_\_\_ [No] - rarely
- \_\_\_ Don't know, no response, unclear response

8. Are you ever afraid or scared when you are out in your neighborhood?

- \_\_\_ [Yes] - most of the time
- \_\_\_ Sometimes
- \_\_\_ [No] - rarely
- \_\_\_ Don't know, no response, unclear response

9. Do you have a provider that helps you where you live? (Does s/he help you with cooking, cleaning, budgeting, etc?)

- \_\_\_ Yes
- \_\_\_ No
- \_\_\_ Don't know, no response, unclear response

10. Does s/he help you meet your independent living goals?

- \_\_\_ Yes
- \_\_\_ Sometimes
- \_\_\_ No
- \_\_\_ Don't know, no response, unclear response

11. Do people let you know before they come into your home? (*Do they ring the doorbell or knock first and wait for an answer?*)

- \_\_\_ Yes
- \_\_\_ Sometimes
- \_\_\_ No
- \_\_\_ Don't know, no response, unclear response

12. Let me check - are you feeling sad or happy today?  
This is a consistency check question – do not rephrase.

- \_\_\_ Happy
- \_\_\_ In-between
- \_\_\_ Sad
- \_\_\_ Don't now, no response, unclear response

## Friends and Family

13. Now I'm going to ask you about friends.  
Do you have friends you like to talk to or do things with?



If s/he answers "yes," ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: *Can you tell me their names? Are these friends, staff, or your family?*

- ☐ Yes, has friends who are not staff or family
- ☐ Yes, all friends are staff or family, or cannot determine
- ☐ No, does not have friends
- ☐ Don't know, no response, unclear response

If the person responds "NO" TO QUESTION 13, code Questions 14-15 as "NOT APPLICABLE."

14. Do you have a best friend, or someone you are really close to? (*Is there someone you can talk to about personal things?*)  
It doesn't matter if they are family or staff here.

- ☐ **NOT APPLICABLE** - does not have friends
- ☐ Yes
- ☐ No
- ☐ Don't know, no response, unclear response

15. Can you see your friends when you want to see them? (*Can you make plans with your friends when you want to?*)  
We are trying to determine if the person gets support to see friends. Try to factor out situations where friends are not available – this is not the issue.

- ☐ **NOT APPLICABLE** – does not have any friends
- ☐ Yes, can see friends whenever s/he wants to
- ☐ Sometimes can't see friends (e.g. not enough transportation)
- ☐ No, often unable to see friends
- ☐ Don't know, no response, unclear response

16. Are you happy with your personal life, or do you feel unhappy?

- ☐ Happy
- ☐ In-between
- ☐ Unhappy
- ☐ Don't know, no response, unclear response

17. Do you ever feel lonely?  
If s/he responds "yes," probe to determine how often s/he feels lonely.

- \_\_\_ [Yes] – often feels lonely
- \_\_\_ Sometimes
- \_\_\_ [No] – not often
- \_\_\_ Don't know, no response, unclear response

18. Do you have family that you see?

If the person lives with family, ask about other family members that do not live in the home.

Can you see your family when you want to? (*Can you pick the times you see them? Does someone help you make plans to see them?*)

If family is not available or does not wish to have contact, code as "NOT APPLICABLE." If the person has family but does not want to see them, code as "2."

- \_\_\_ **NOT APPLICABLE** – family not available or family does not wish to have contact
- \_\_\_ Yes, sees family whenever s/he wants to, or chooses not to see family
- \_\_\_ Sometimes
- \_\_\_ No
- \_\_\_ Don't know, no response, unclear response

## Services/Supports Coordination:

If the person says they do not know their coordinator, code questions 19-25 as "No."

19. Do you know your coordinator?

- \_\_\_ Yes, person knows coordinator
- \_\_\_ Maybe, not sure
- \_\_\_ No, person does not know coordinator
- \_\_\_ Don't know, no response, unclear response

20. If you ask for something, does s/he help you get what you need?

- \_\_\_ Yes, does help
- \_\_\_ Sometimes helps
- \_\_\_ No, does not help or person does not know coordinator
- \_\_\_ Don't know, no response, unclear response

21. Does s/he ask you what you want?

- ☐ Yes, does ask
- ☐ Sometimes helps
- ☐ No, does not ask or person does not know coordinator
- ☐ Don't know, no response, unclear response

22. Does s/he help you to make a plan to get what you want and need?

- ☐ Yes, does ask
- ☐ Sometimes helps
- ☐ No, does not help or person does not know coordinator
- ☐ Don't know, no response, unclear response

23. Does the Coordinator help you do or learn new things?

- ☐ Yes, always helps
- ☐ Sometimes helps
- ☐ No, never helps
- ☐ Don't know, no response, unclear response

24. Does the Coordinator help you to find resources or people who can help you?

- ☐ Yes, always helps
- ☐ Sometimes helps
- ☐ No, never helps
- ☐ Don't know, no response, unclear response

25. Are you happy with the services that you receive from the Coordinator?

- ☐ Yes
- ☐ Sometimes
- ☐ No or person does not know coordinator
- ☐ Don't know, no response, unclear response

26. When you want to go somewhere, do you always have a way to get there? (*Can you get a ride when you need one?*)

- ☐ Yes, almost always
- ☐ Sometimes

- ☐ No, almost never
- ☐ Don't know, no response, unclear response

## Self-Determination

27. Do you know how much money is spent on paying for your providers?

- ☐ Yes
- ☐ Maybe, not sure
- ☐ No
- ☐ Don't know, no response, unclear response

28. When you have your annual meeting, does someone tell you how much money is in your budget?

- ☐ Yes
- ☐ Maybe, not sure
- ☐ No
- ☐ Don't know, no response, unclear response

29. Interviewer: Could this section be completed?

- ☐ Yes, person answered independently or with some assistance
- ☐ Yes, person answered using alternative/picture response format
- ☐ No, person could not communicate sufficiently to complete this section
- ☐ No, person was unwilling to participate
- ☐ No, other reason

30. Interviewer: In your opinion, did the individual understand most of the questions or not?

- ☐ **NOT APPLICABLE** – did not complete
- ☐ Yes, understood most questions (even if prompted) and could give an opinion
- ☐ Not sure
- ☐ No, very little understanding or no comprehension

31. Interviewer: In your opinion, did the individual answer the questions in a consistent manner? (Do you feel his/her responses were valid?)

- \_\_\_ **NOT APPLICABLE** – did not complete
- \_\_\_ Yes, gave consistent and valid responses
- \_\_\_ Not sure
- \_\_\_ No, did not give consistent and valid responses

If the participant is not willing to continue, or if you believe comprehension or consistency was a problem, then say:

*"Thank you for your help. It's been very nice talking to you. You've been very helpful."*

Otherwise, continue to the next section.

Ask the person if s/he wishes to continue with the questions, or if s/he would like to take a short break.

## Community Involvement

In this section, we are trying to find out if the person participates in community activities. Try to rule out non-integrated activities, for example, Special Olympics. If the person answers "yes," you may ask for an example to verify that the person understood the question.

32. Do you go shopping? (*What do you go shopping for? Examples: groceries, clothing, house-wares, tapes/CDs.*)

- \_\_\_ Yes
- \_\_\_ No
- \_\_\_ No response, unclear, don't know

33. Do you go out on errands or appointments? (*Where do you go? Examples: doctor, dentist, bank, post office, hair dressers/barber.*)

- \_\_\_ Yes
- \_\_\_ No
- \_\_\_ No response, unclear, don't know

34. Do you go out for entertainment? (*Where do you go? Examples: movies, library, plays, concerts, museums, art galleries.*)

- \_\_\_ Yes
- \_\_\_ No
- \_\_\_ No response, unclear, don't know

35. Do you always eat at home, or do you sometimes go out to eat? (*Where do you go to eat?*)
- \_\_\_ Sometimes goes out to eat
- \_\_\_ Always eats at home
- \_\_\_ No response, unclear, don't know
36. Do you go to religious services? (*Where do you go? Examples: church, synagogue, or other place of worship.*)
- \_\_\_ Yes
- \_\_\_ No
- \_\_\_ No response, unclear, don't know
37. Do you go to clubs or other community meetings? (*Where do you go? Examples: non-religious clubs, social groups or community organizations.*)
- \_\_\_ Yes
- \_\_\_ No
- \_\_\_ No response, unclear, don't know
38. Do you exercise or play sports? (*What kind of exercise? Examples: jogging, swimming, riding bike, etc.*)
- \_\_\_ Yes
- \_\_\_ No
- \_\_\_ No response, unclear, don't know

## Choices

The intent of these questions is to determine if people receiving services are involved in decision-making. Choices made with spouses/partners should be coded as "without help."

Read the following introduction to the participant:

I'm going to ask you questions about some decisions you may have made or helped make. For each question, I'd like you to tell me if you made the choice by yourself, if you had some say about it, or if someone else decided for you.

39. Who chose (or picked) the place where you live? (*Did you choose by yourself or with help?*)
- \_\_\_ **NOT APPLICABLE** – lives with family

- \_\_\_ Person chose without help
- \_\_\_ Person had some input
- \_\_\_ Someone else chose
- \_\_\_ Don't know, no response, unclear response

40. How many places did you visit before moving here?

- \_\_\_ **NOT APPLICABLE** – lives with family
- \_\_\_ Looked at more than one place
- \_\_\_ Visited one place only
- \_\_\_ Did not visit before moving in
- \_\_\_ Don't know, no response, unclear response, can't remember – too long ago

41. Did you choose (or pick) the people you live with (or did you choose to live by yourself)?

- \_\_\_ **NOT APPLICABLE** – lives with family
- \_\_\_ Yes, chose people s/he lives with, or chose to live alone
- \_\_\_ Chose some people or had some input
- \_\_\_ No, someone else chose
- \_\_\_ Don't know, no response, unclear response

43. Did you choose (or pick) who helps you at home? *(Did you get to interview them? If you wanted to change, could you ask for someone different?)*

- \_\_\_ **NOT APPLICABLE** - no providers in the home
- \_\_\_ Yes, person chooses providers
- \_\_\_ No, someone else chooses
- \_\_\_ Don't know, no response, unclear response

44. Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?

- \_\_\_ Person decides
- \_\_\_ Person has help deciding
- \_\_\_ Someone else decides
- \_\_\_ Don't know, no response, unclear response

45. Who decides how you spend your free time (when you are not working, volunteering, or in school)?

- \_\_\_ Person decides

- \_\_\_ Person has help deciding
- \_\_\_ Someone else decides
- \_\_\_ Don't know, no response, unclear response

46. Who chose (or picked) the place where you work or volunteer (or go during the day)? *(Did you choose by yourself or with help?)*

- \_\_\_ **NOT APPLICABLE** – no work or day activity
- \_\_\_ Person chose without help
- \_\_\_ Person had some input
- \_\_\_ Someone else chose
- \_\_\_ Don't know, no response, unclear response

47. How many places did you visit before working (going) there?

- \_\_\_ **NOT APPLICABLE** – no work or day activity
- \_\_\_ Looked at more than one place
- \_\_\_ Visited one place only
- \_\_\_ Did not visit beforehand
- \_\_\_ Don't know, no response, unclear response, can't remember – too long ago

48. Do you choose what you buy with your spending money? *(Do not include things like rent or groceries.)*

- \_\_\_ Person chooses
- \_\_\_ Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)
- \_\_\_ Someone else chooses
- \_\_\_ Don't know, no response, unclear response

49. Did you choose or pick your coordinator? *(Could you request someone different?)*

- \_\_\_ Yes, chose coordinator
- \_\_\_ Coordinator was assigned but s/he can request a change if not satisfied
- \_\_\_ No, someone else chose coordinator
- \_\_\_ Don't know, no response, unclear response

## Rights



50. Do people read your mail without your permission?

- ☐ **NOT APPLICABLE** - does not get mail
- ☐ [Yes] – mail is always read without permission
- ☐ Some mail is read without permission
- ☐ [No] – person reads own mail or others read with permission
- ☐ Don't know, no response, unclear response

51. Do your friends ever come over to visit?

If no, code as "NOT APPLICABLE." If yes, ask:

Can you be alone with them, or does someone have to be with you? (*Are there rules about having friends over?*)

- ☐ **NOT APPLICABLE** – no friends or friends do not visit
- ☐ Can be alone with friends
- ☐ There are some rules (e.g only in common areas, or not overnight)
- ☐ Someone else always has to be present
- ☐ Don't know, no response, unclear response

52. Are you allowed to use the phone when you want to?

- ☐ **NOT APPLICABLE** - doesn't have phone/TTY or unable to use phone
- ☐ Yes, can use anytime, either independently or with assistance, has own phone, or uses email
- ☐ There are some rules/restrictions on use of phone
- ☐ No, person is not allowed to use phone
- ☐ Don't know, no response, unclear response

## Access to Services

53. Do you get the services you need?

We are only looking for services and supports here, such as companion care, transportation, job coaching, taking a class, getting medical care, etc.

- ☐ Yes
- ☐ Sometimes, or doesn't get enough of the services needed
- ☐ No
- ☐ Don't know, no response, unclear response

If no, what services are needed?

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54. Are you satisfied with the services that you get?

- ☐ Yes, completely
- ☐ Yes, somewhat
- ☐ No
- ☐ Don't know, no response, unclear response

If no, what can you do to change that?

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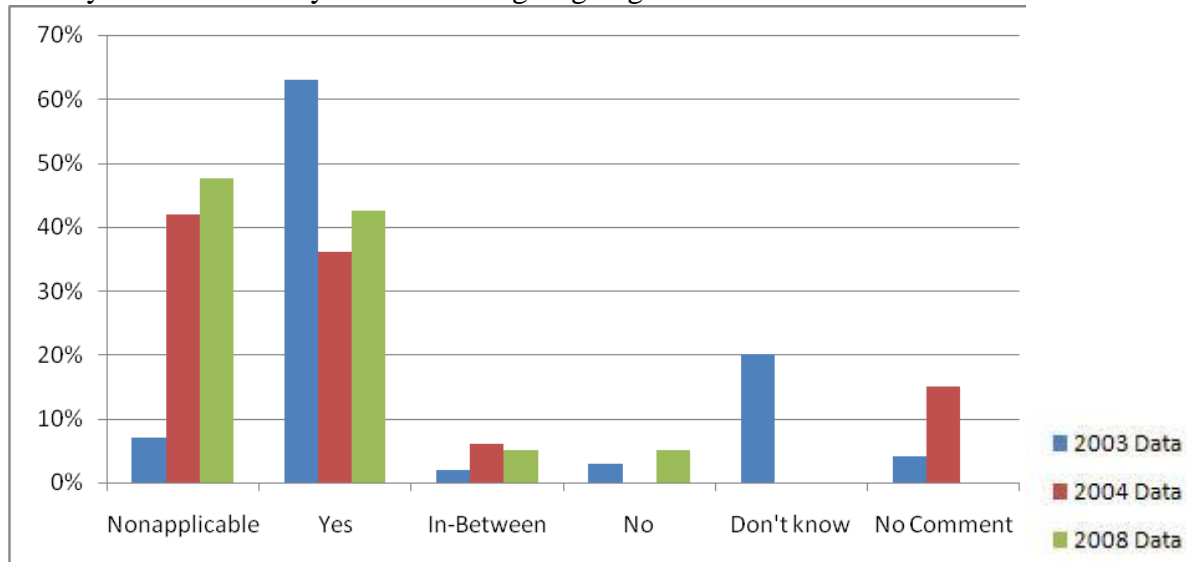
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When you're finished with the interview, thank the person for their time to meet with you.

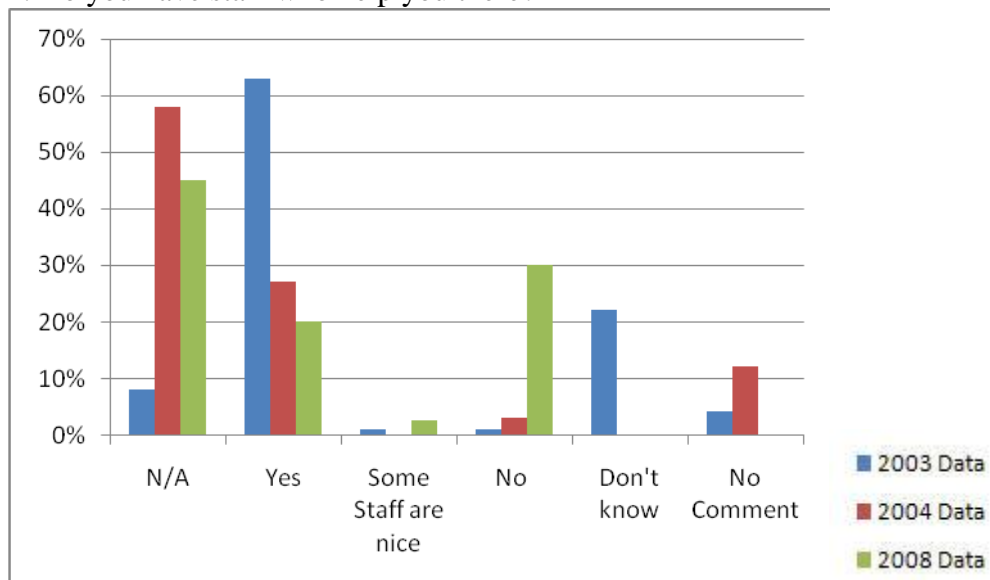
*"Thank you for your help. It's been very nice talking to you. You've been very helpful."*

# Appendix C Results of 2003, 2004, and 2008 responses to all questions.

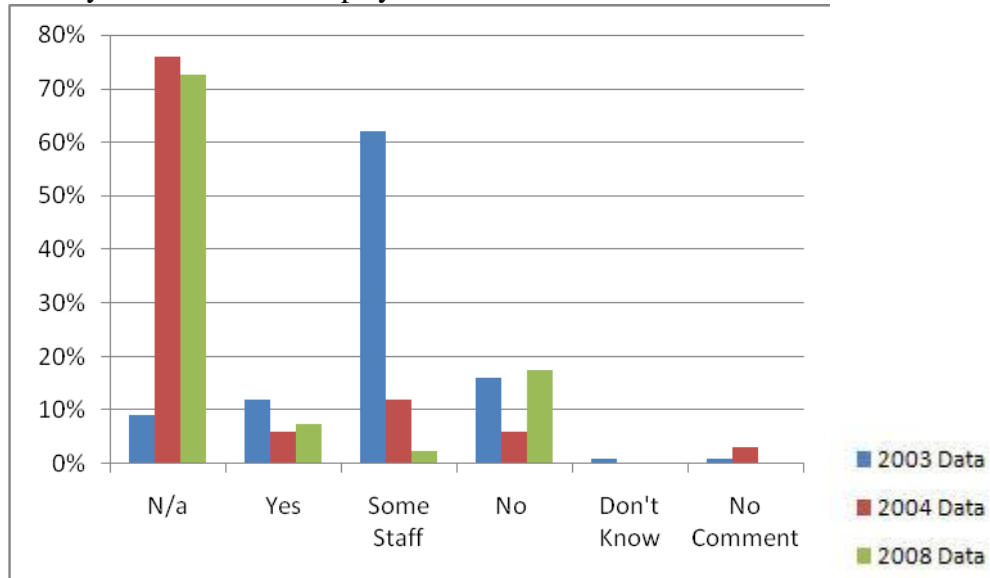
## 1. Do you work and do you like working or going there?



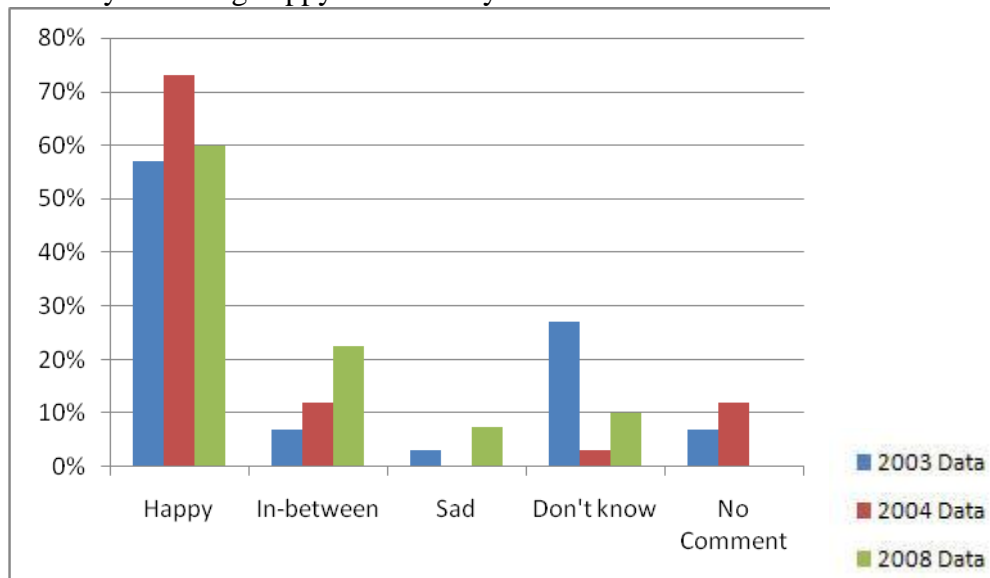
## 2. Do you have staff who help you there?



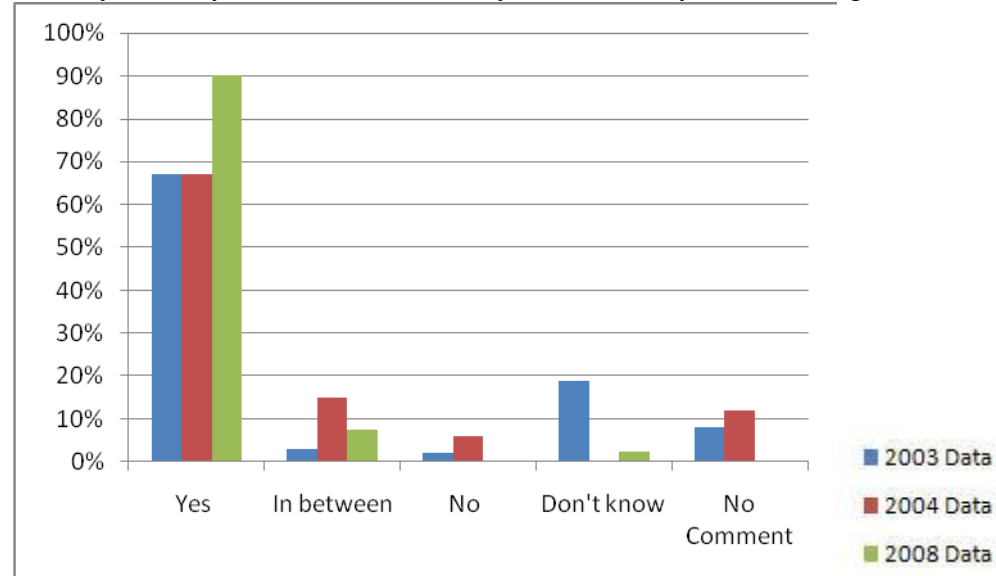
### 3. Do you choose who helps you at work?



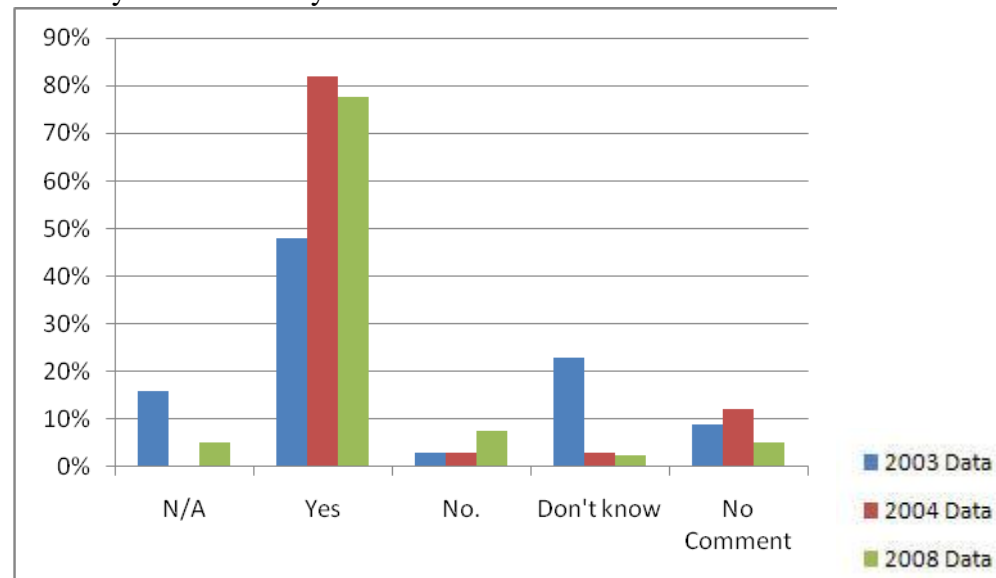
### 4. Are you feeling happy or sad today?



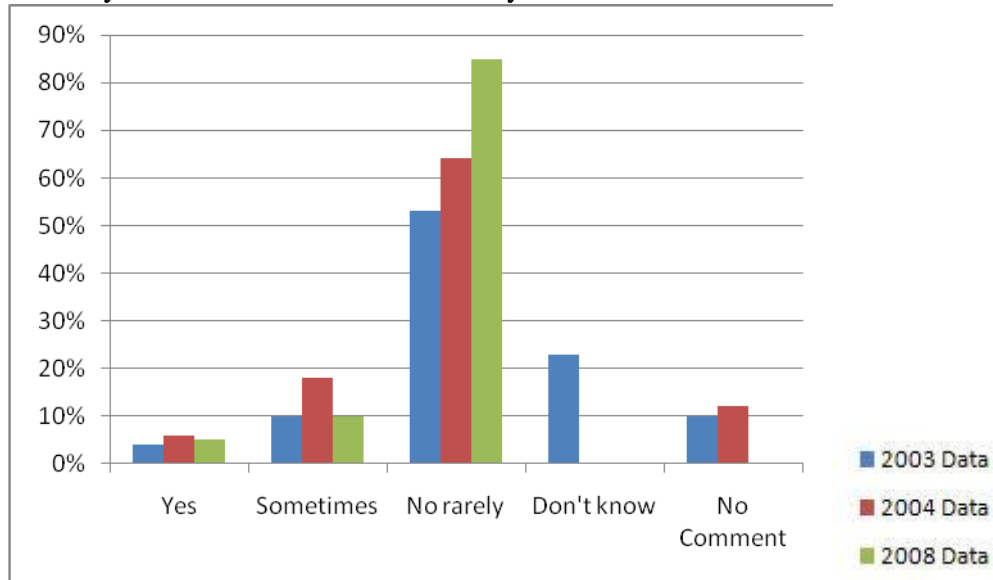
5. Do you like your home and where you live? Do you like living here?



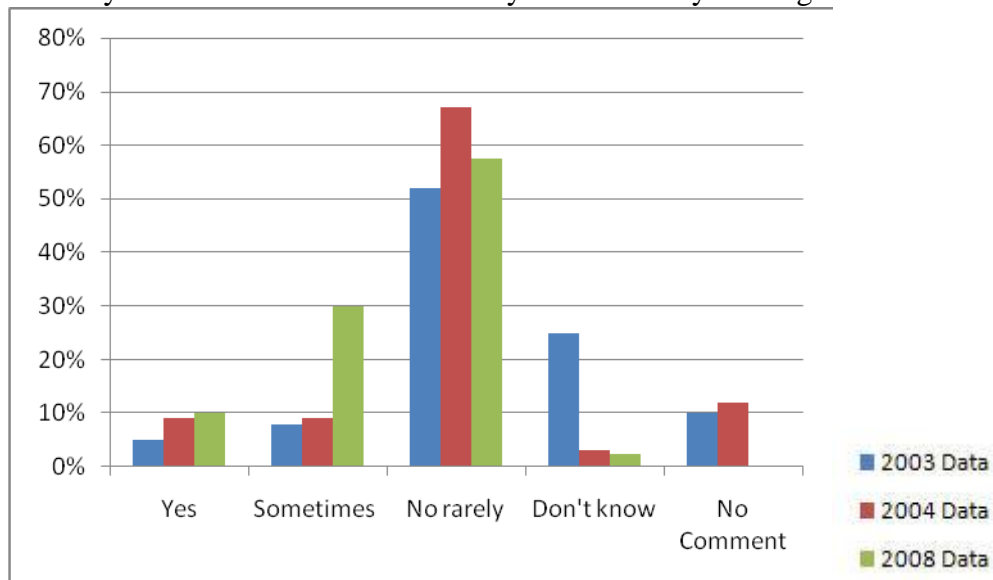
6. Can you be alone if you want to?



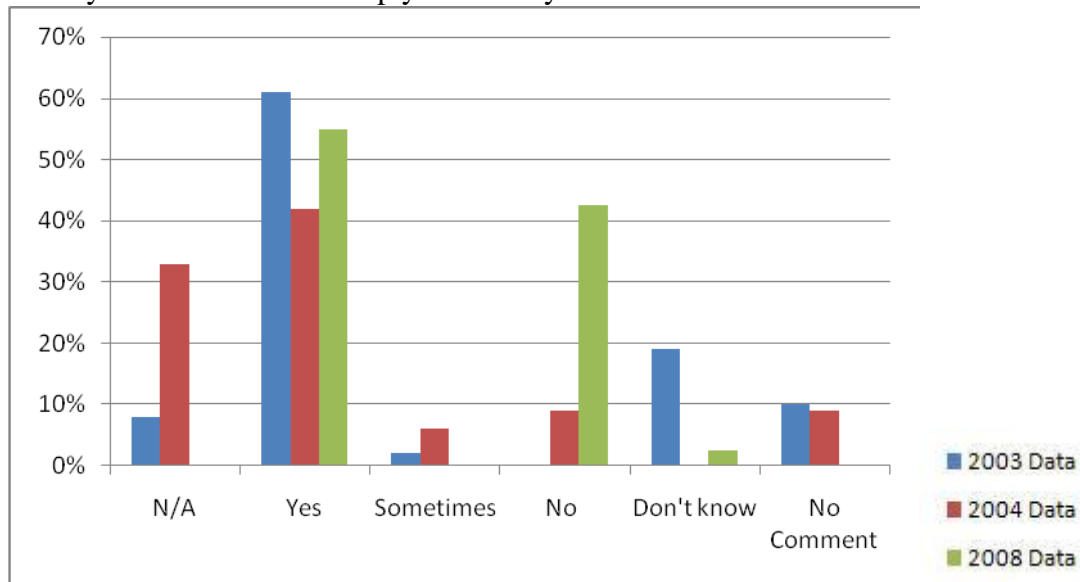
7. Are you ever afraid or scared when you are at home?



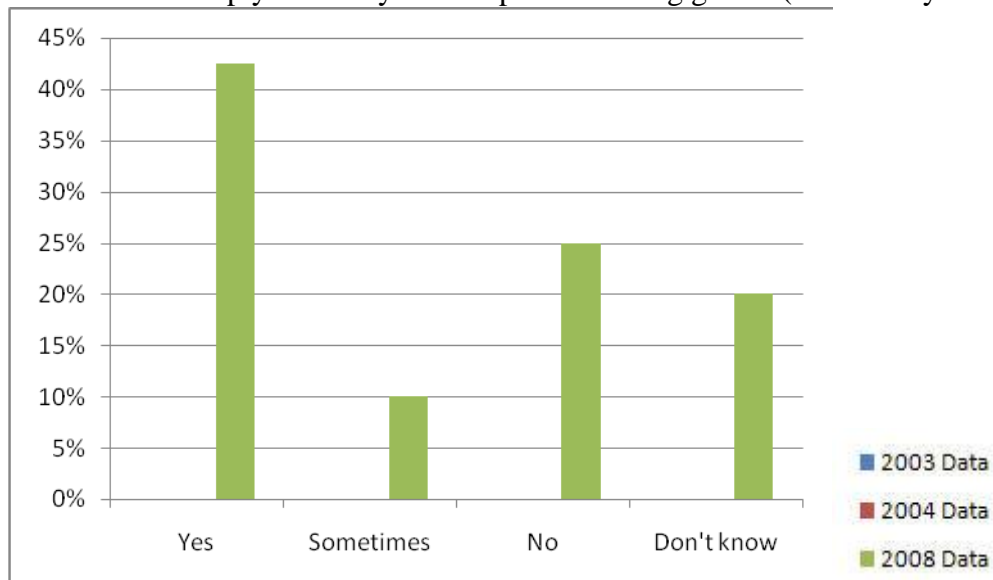
8. Are you ever afraid or scared when you are out in your neighborhood?



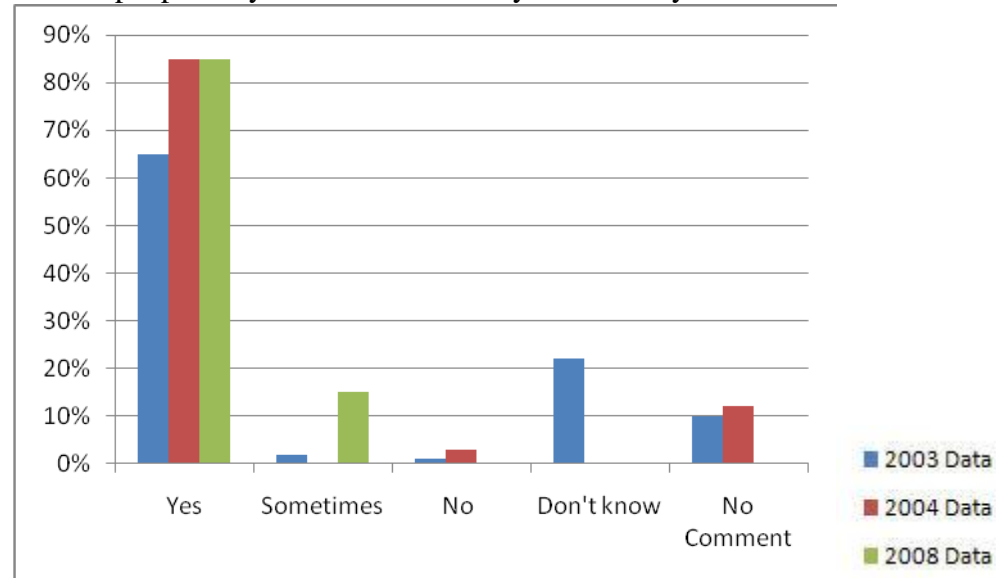
9. Do you have staff who help you where you live?



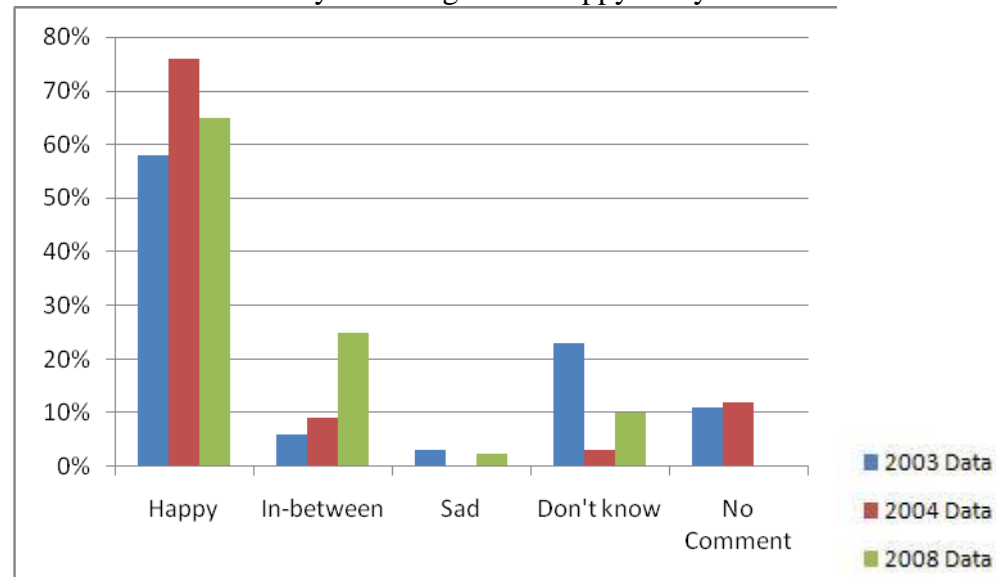
10. Does s/he help you meet your independent living goals? (Asked only in 2008)



11. Do people let you know before they come into your home?

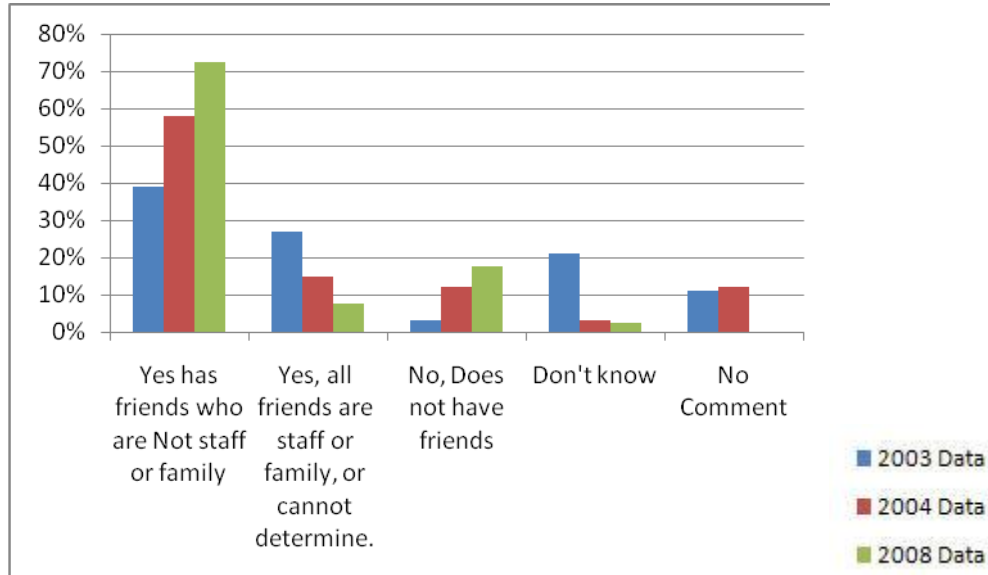


12. Let me check - are you feeling sad or happy today?

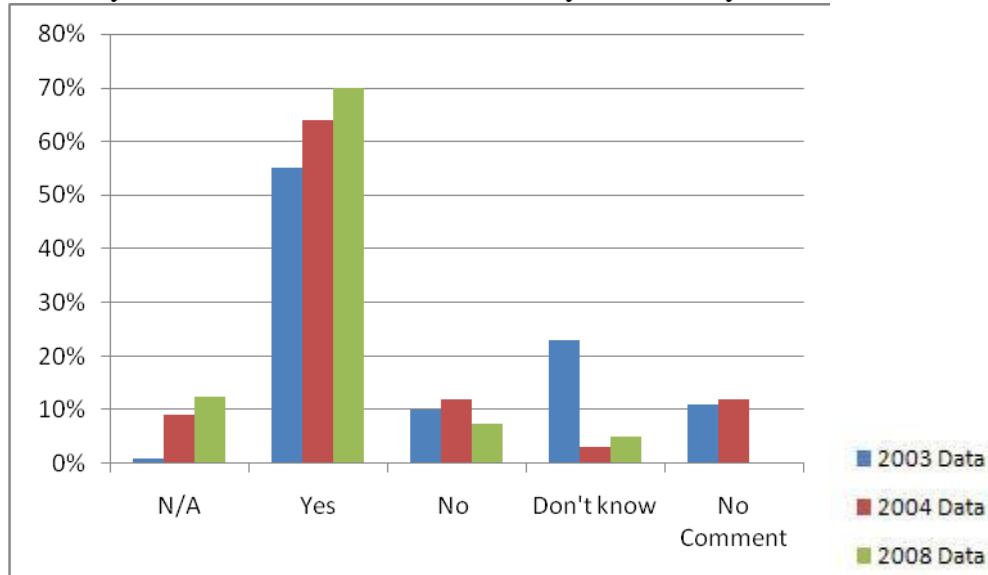




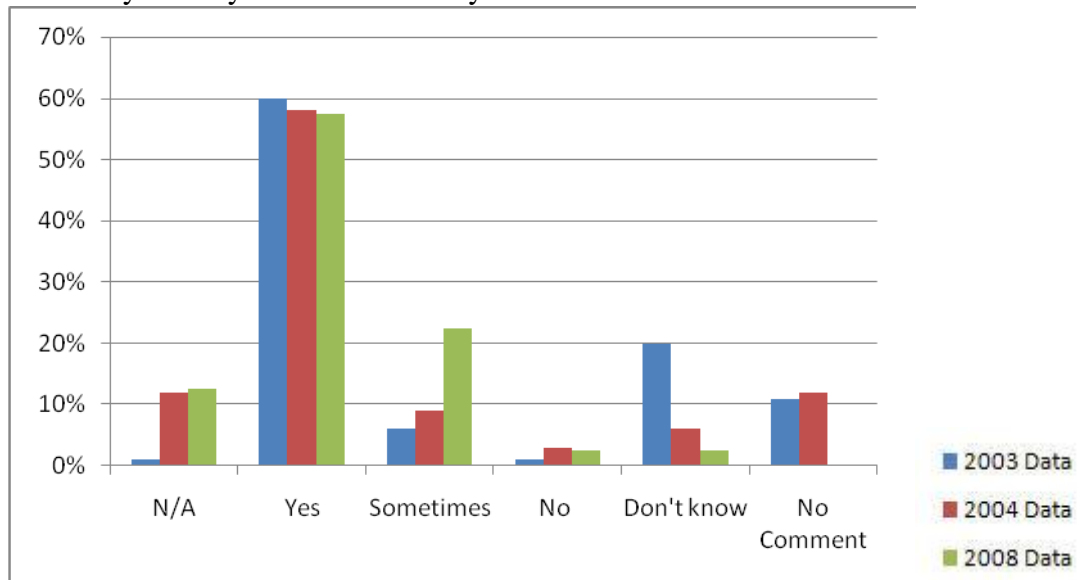
13. Now I'm going to ask you about friends. Do you have friends you like to talk to or do things with?



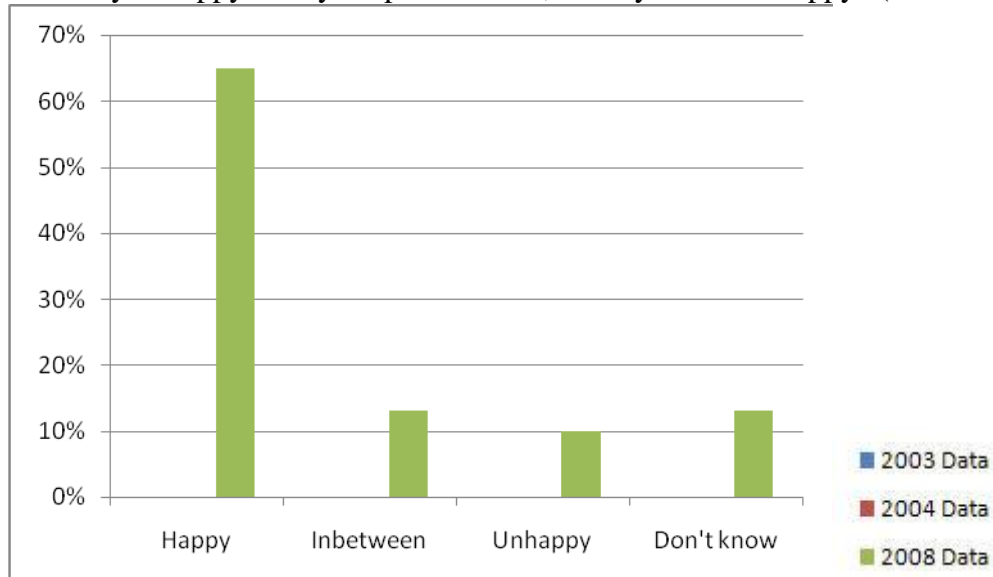
14. Do you have a best friend, or someone you are really close to?



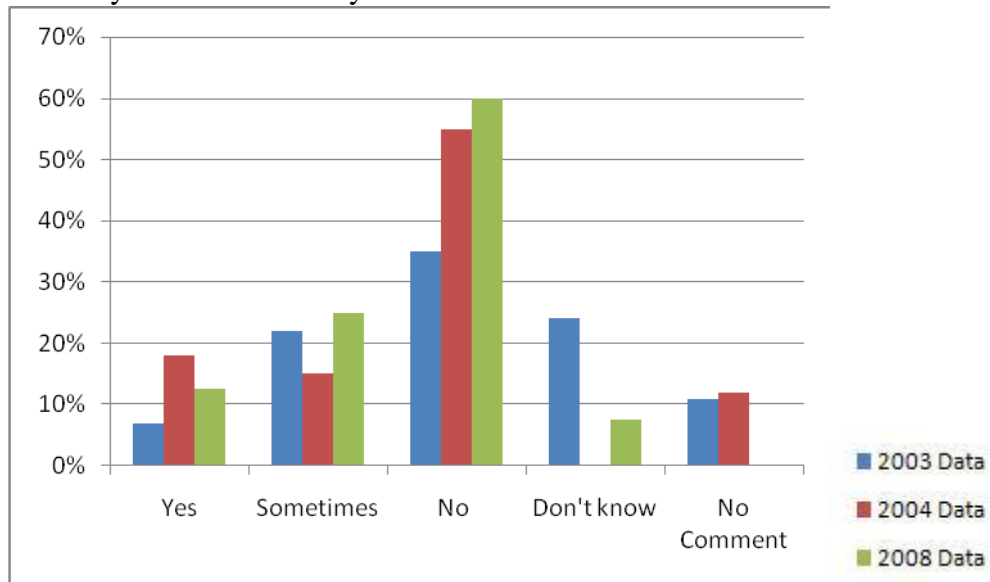
15. Can you see your friends when you want to see them?



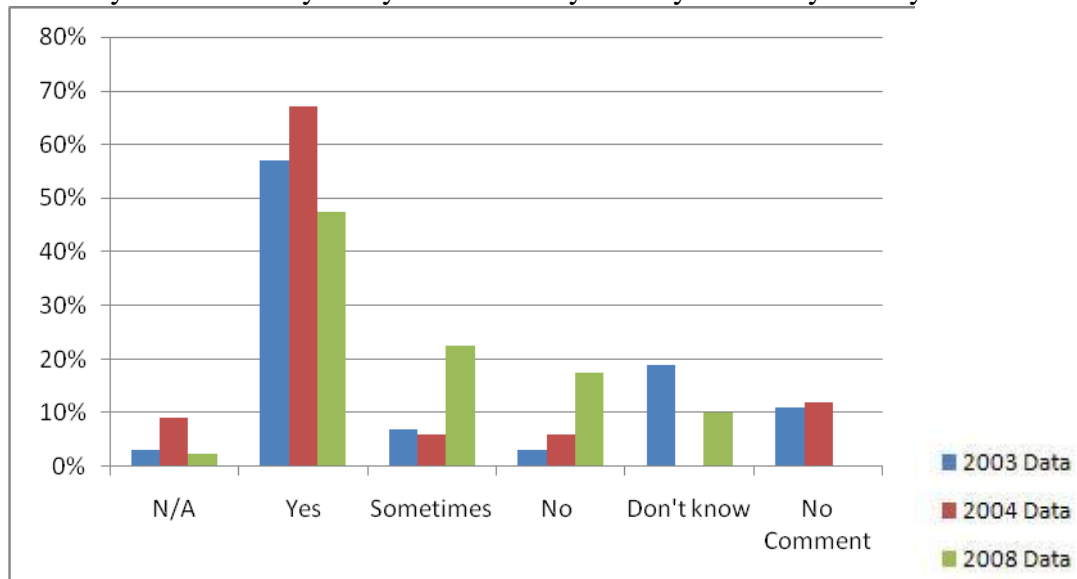
16. Are you happy with your personal life, or do you feel unhappy? (Asked only in 2008)



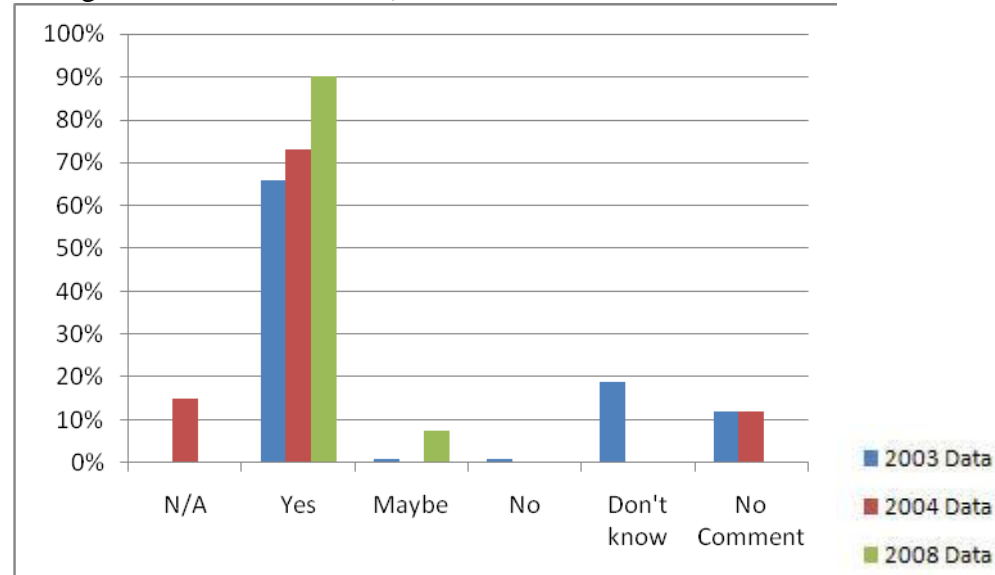
### 17. Do you ever feel lonely?



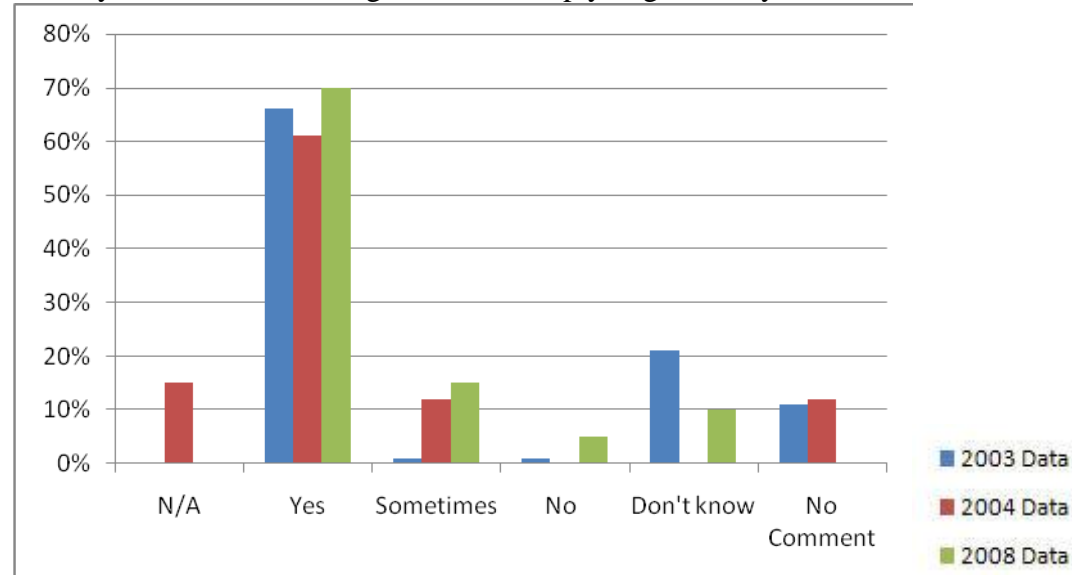
### 18. Do you have family that you see? Can you see your family when you want to?



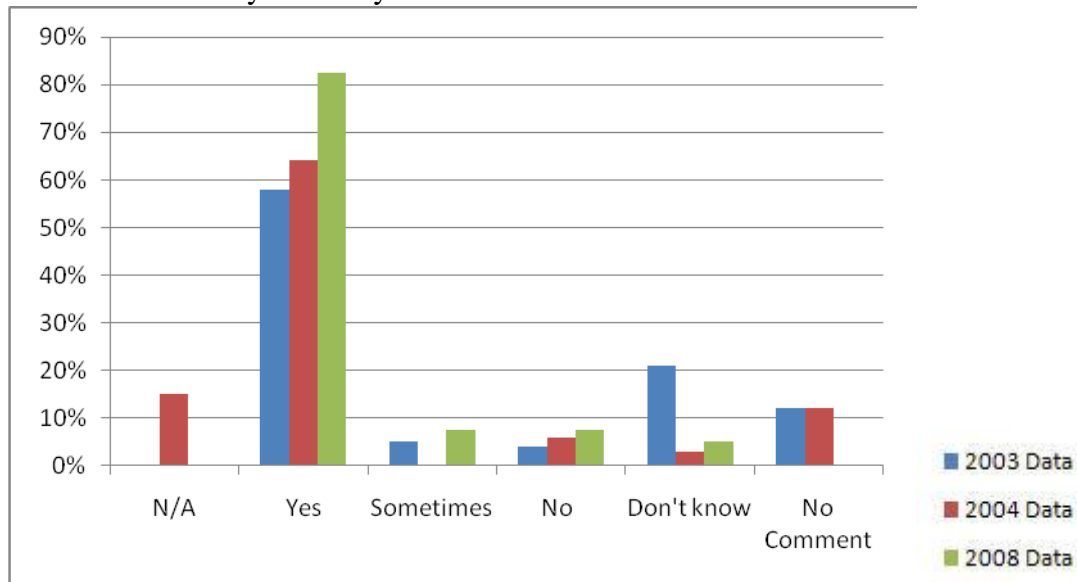
19. Do you know your coordinator? ( Previous wording: Do you know your case manager/service coordinator?)



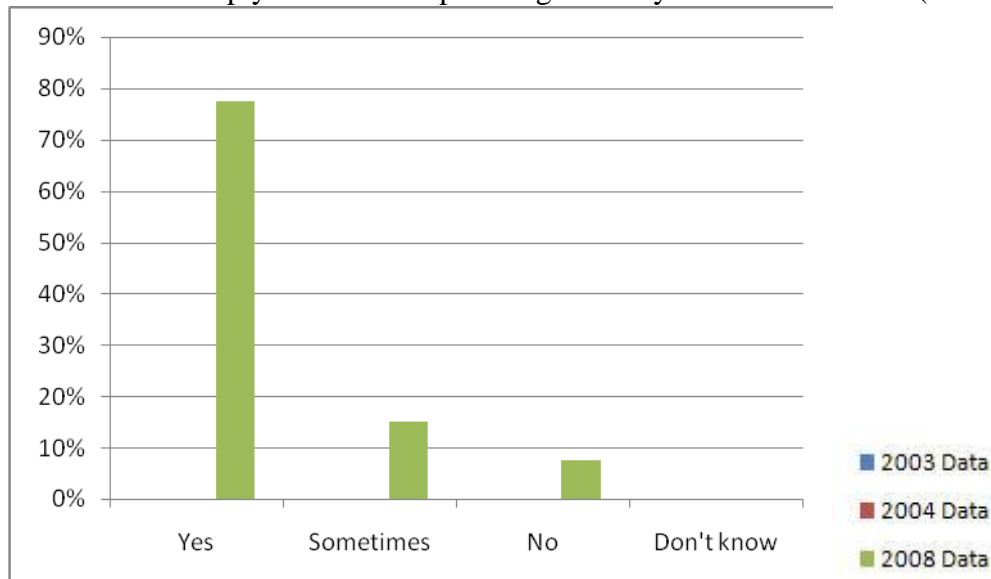
20. If you ask for something, does s/he help you get what you need?



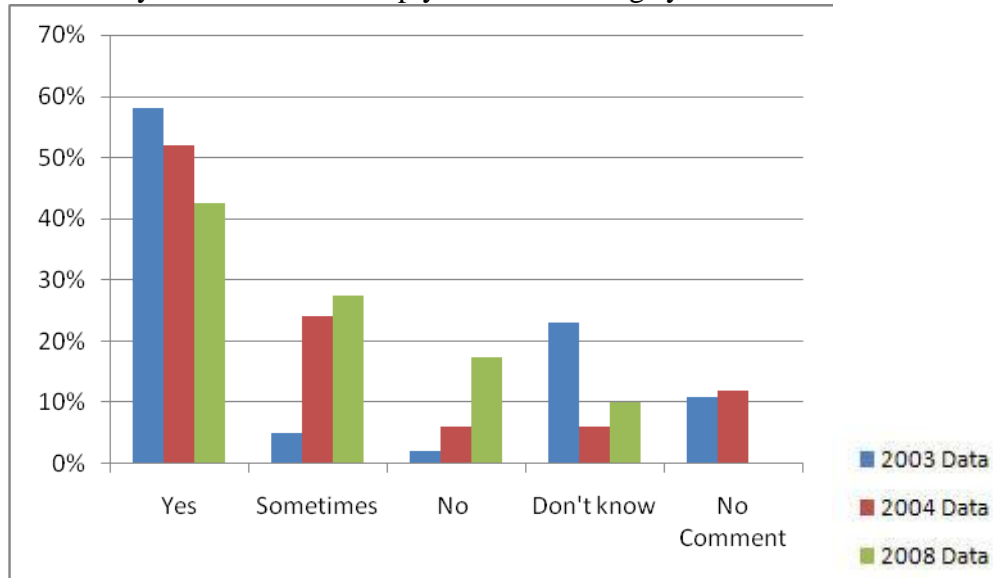
21. Does s/he ask you what you want?



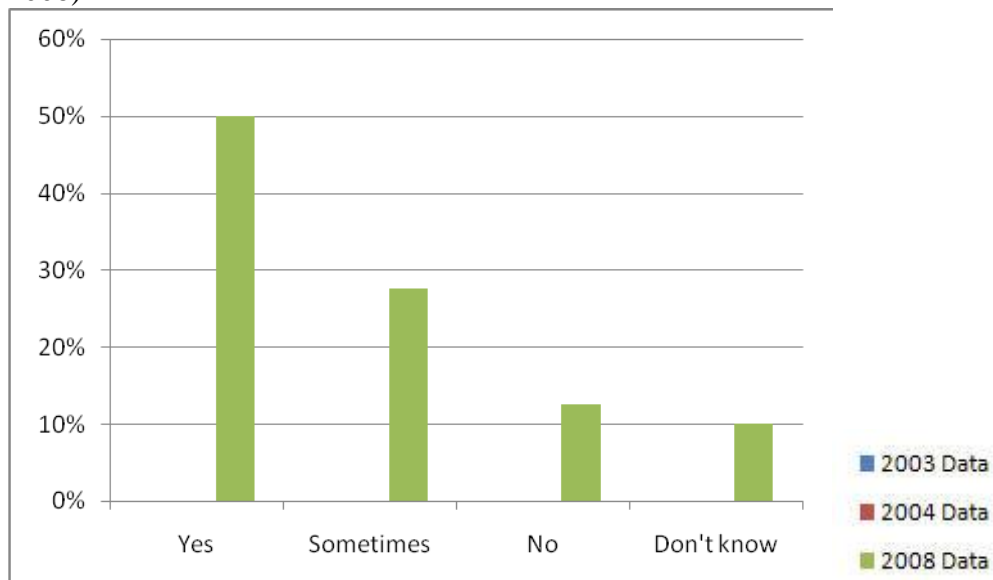
22. Does s/he help you to make a plan to get what you want and need? (Asked only in 2008)



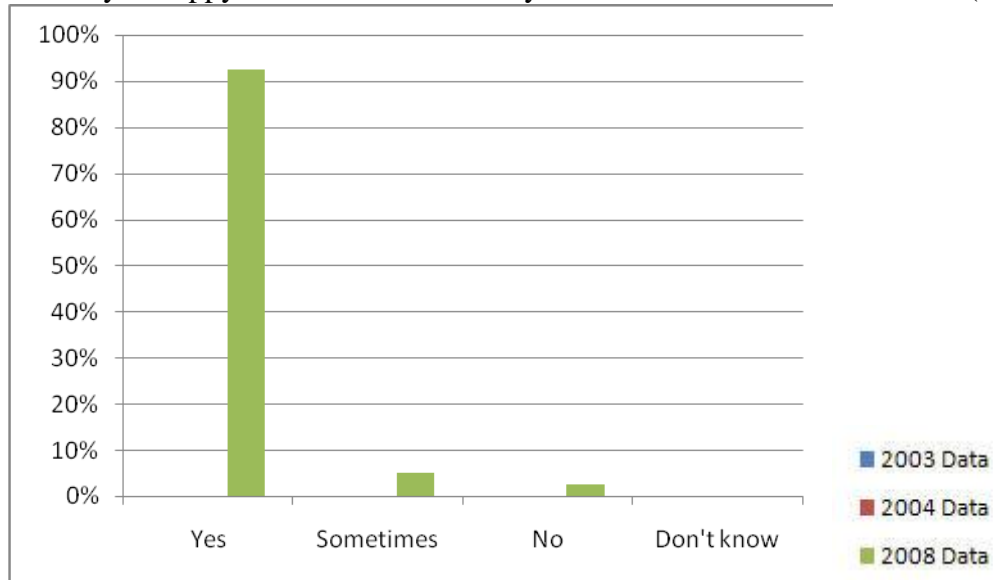
23. Does your coordinator help you do new things you want to do?



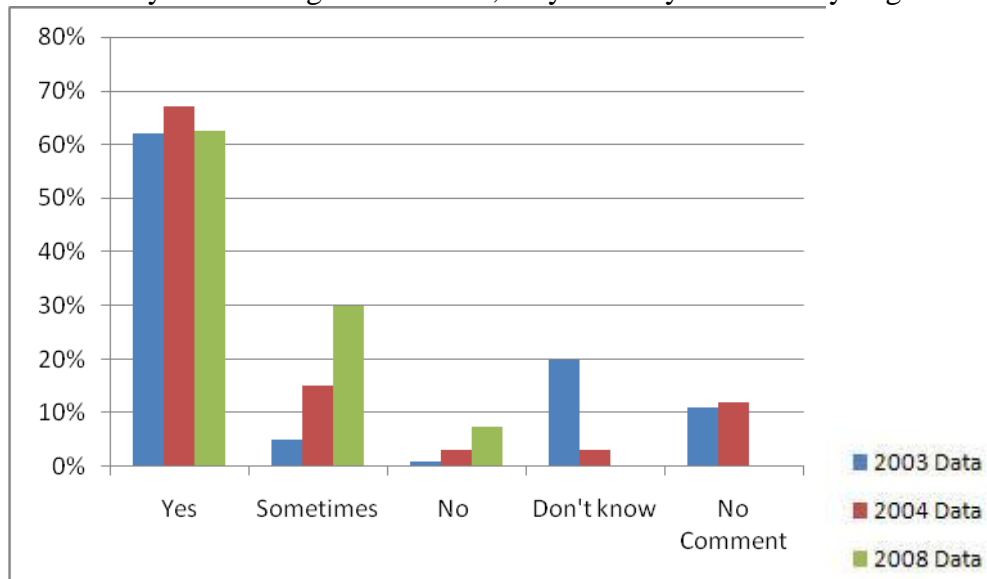
24. Does the coordinator help you to find resources or people who can help you? (Asked only in 2008)



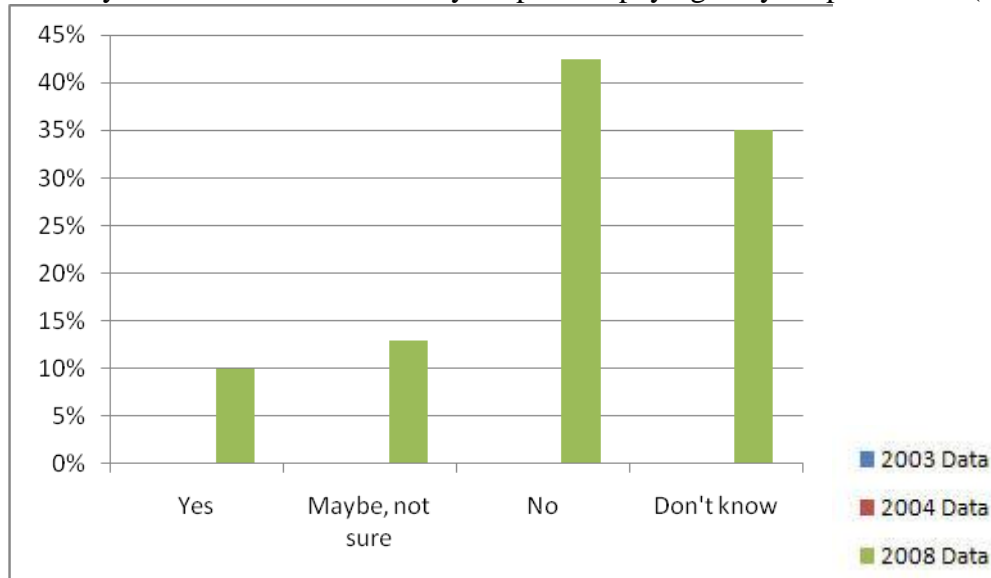
25 Are you happy with the services that you receive from the coordinator? (Asked only in 2008)



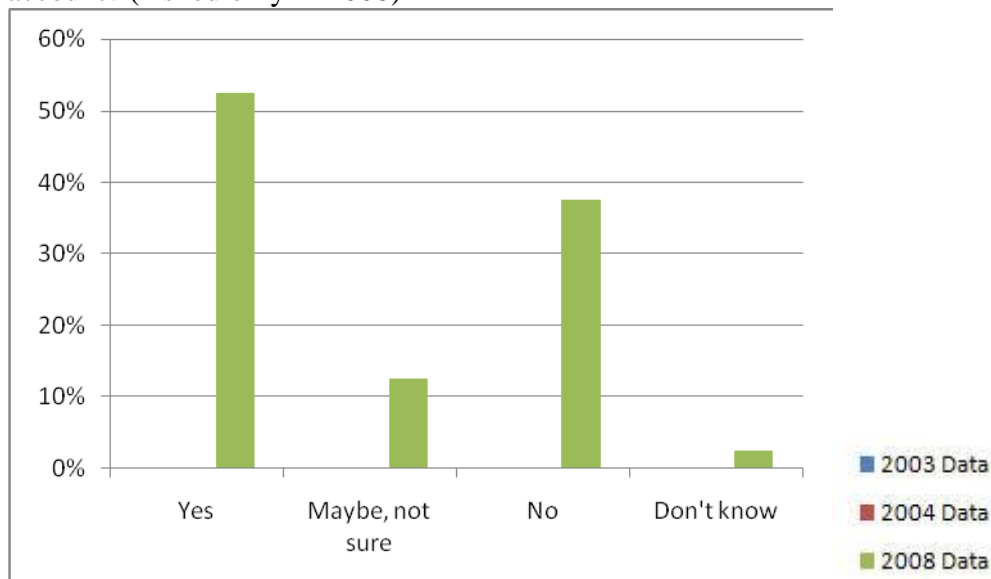
26. When you want to go somewhere, do you always have a way to get there?



27. Do you know how much money is spent on paying for your providers? (Asked only in 2008)

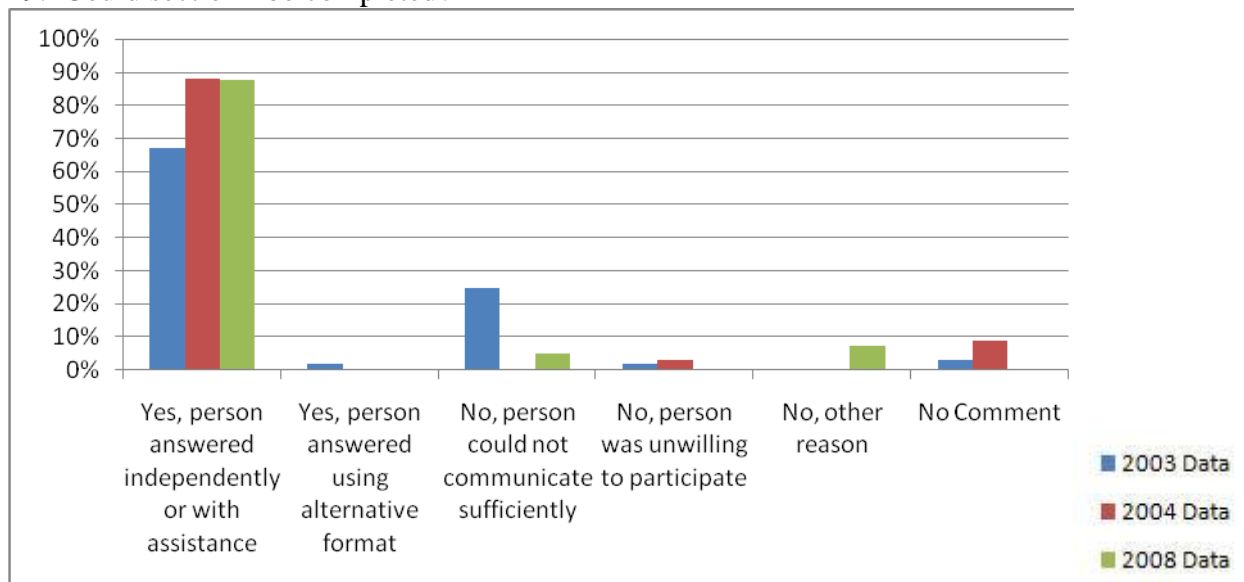


28. When you have your annual meeting, does someone tell you how much money is in your account? (Asked only in 2008)

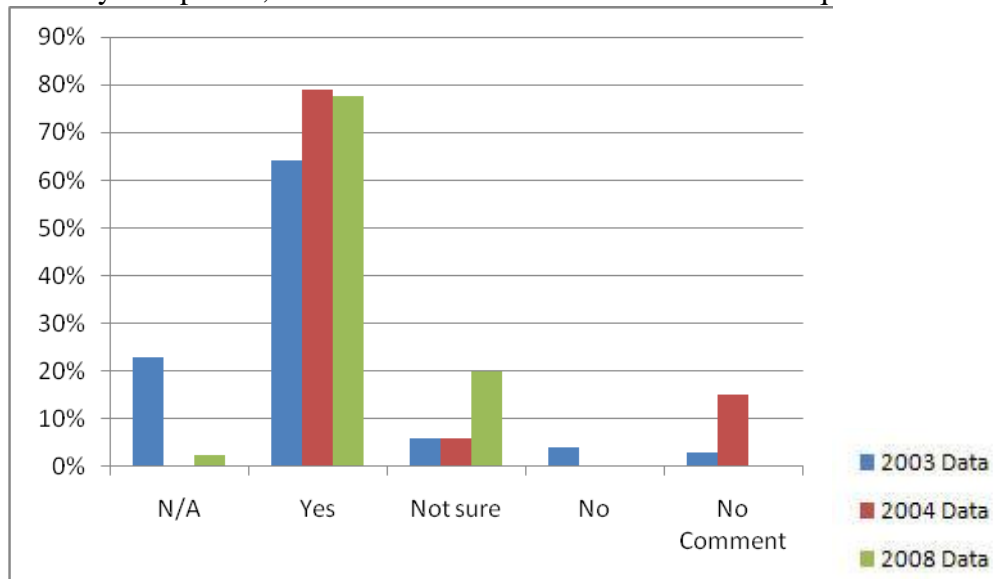




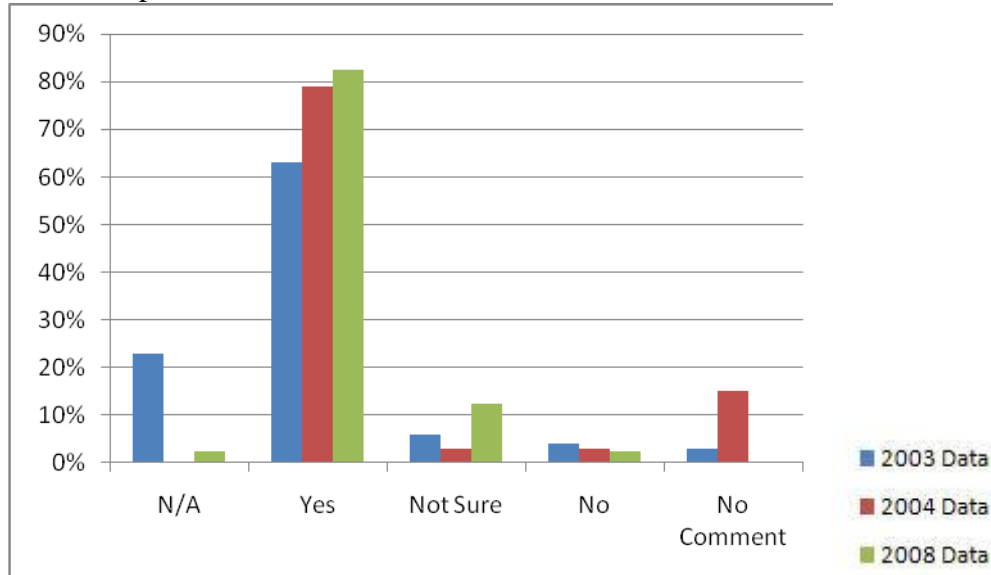
29. Could section I be completed?



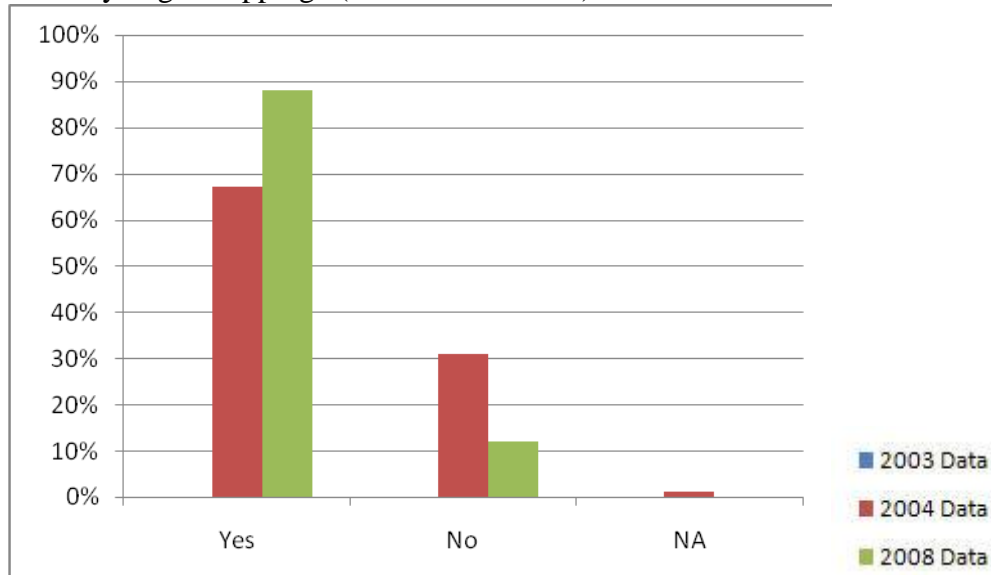
30. In your opinion, did the individual understand most of the questions or not?



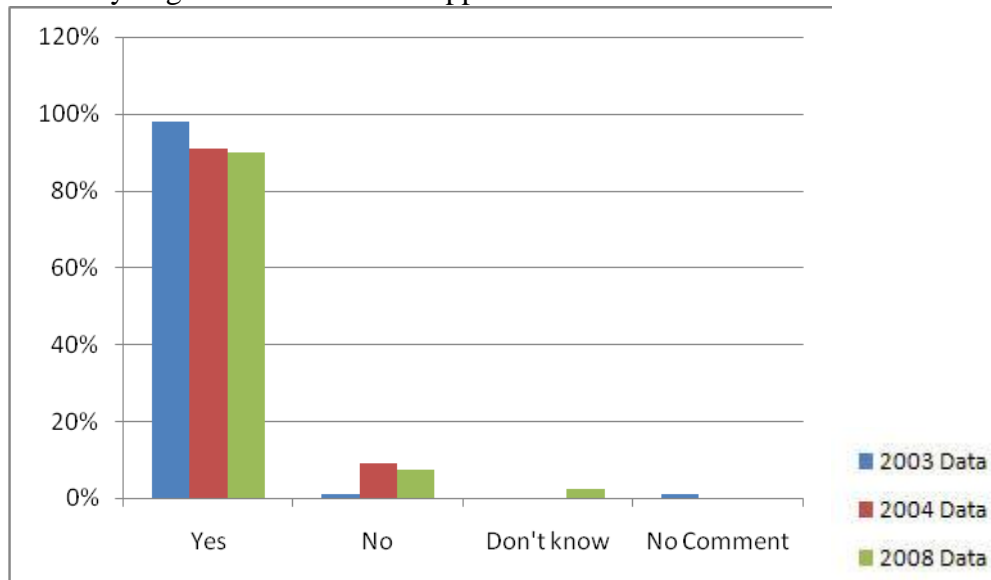
31. In your opinion, did the individual answer the questions in a consistent manner? Do you feel his/her responses were valid?



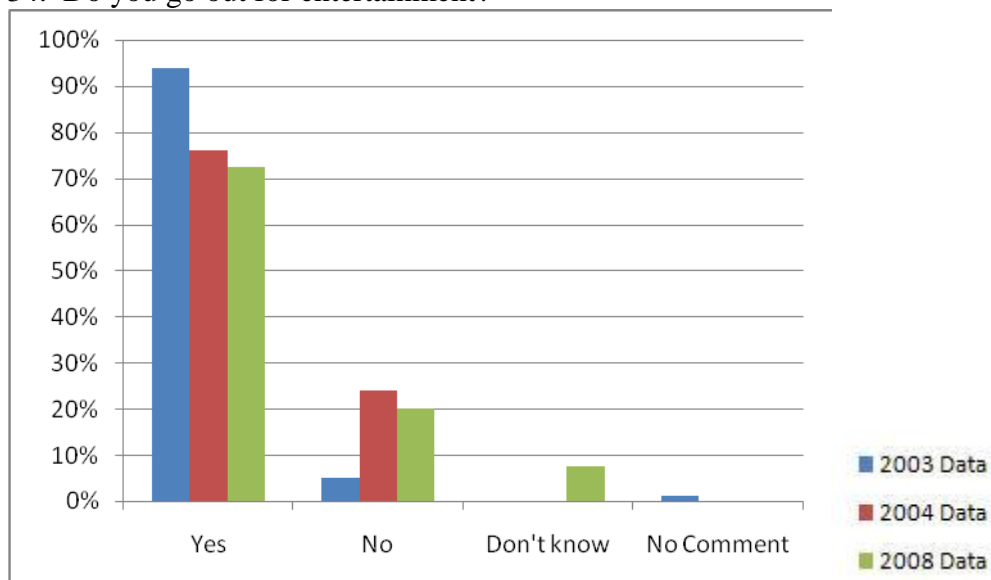
32. Do you go shopping? (Not asked in 2003)



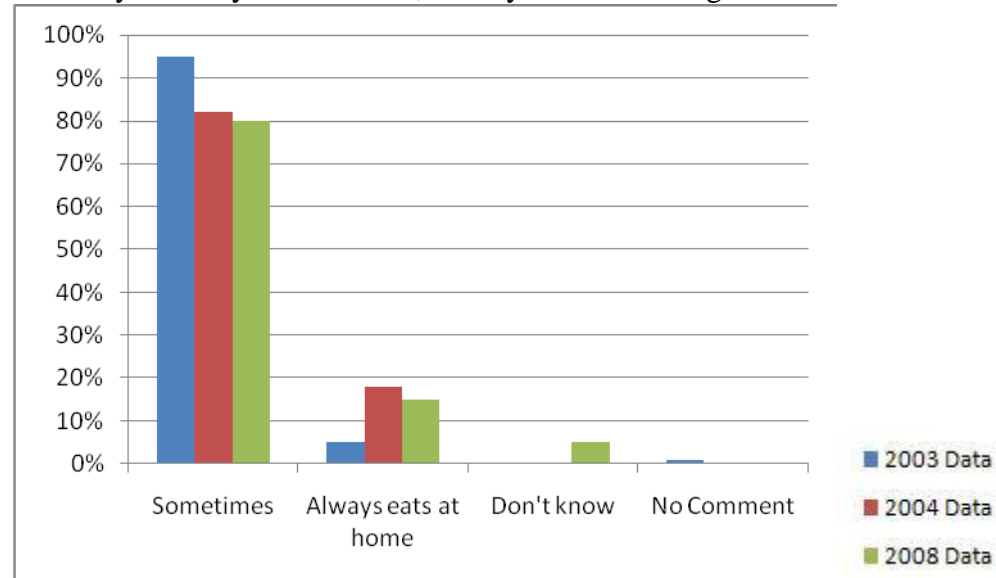
### 33. Do you go out on errands or appointments?



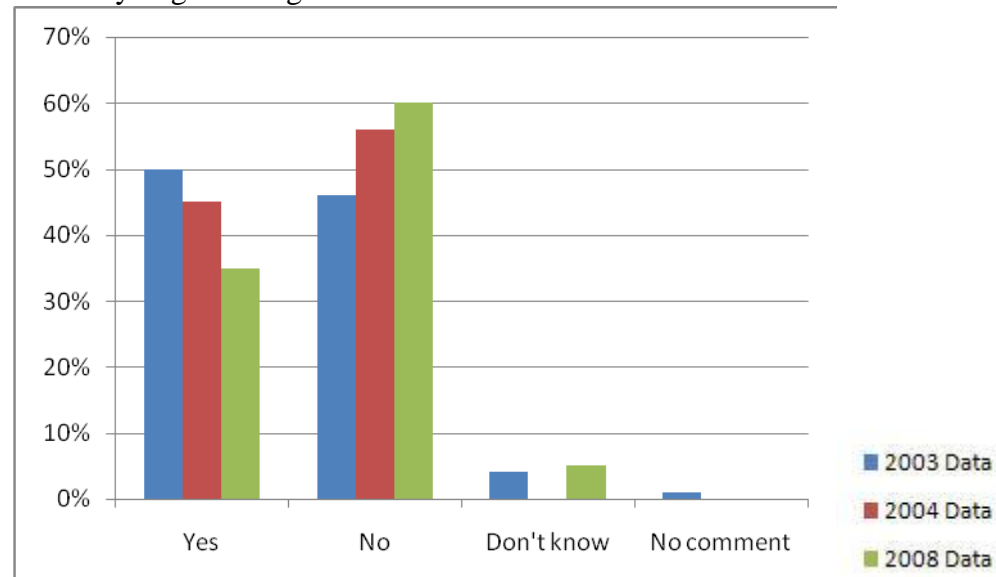
### 34. Do you go out for entertainment?



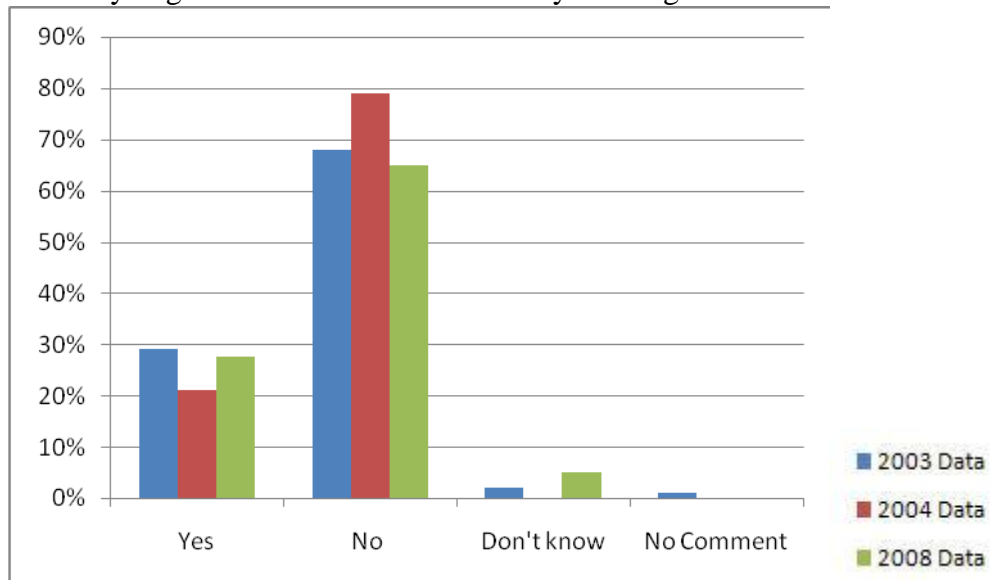
35. Do you always eat at home, or do you sometimes go out to eat?



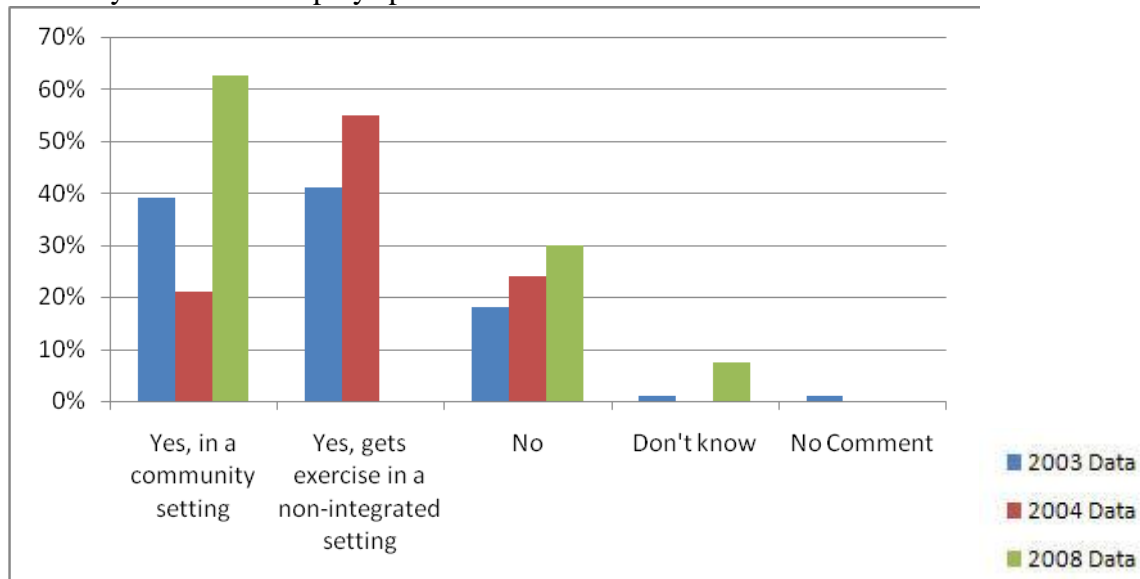
36. Do you go to religious services?



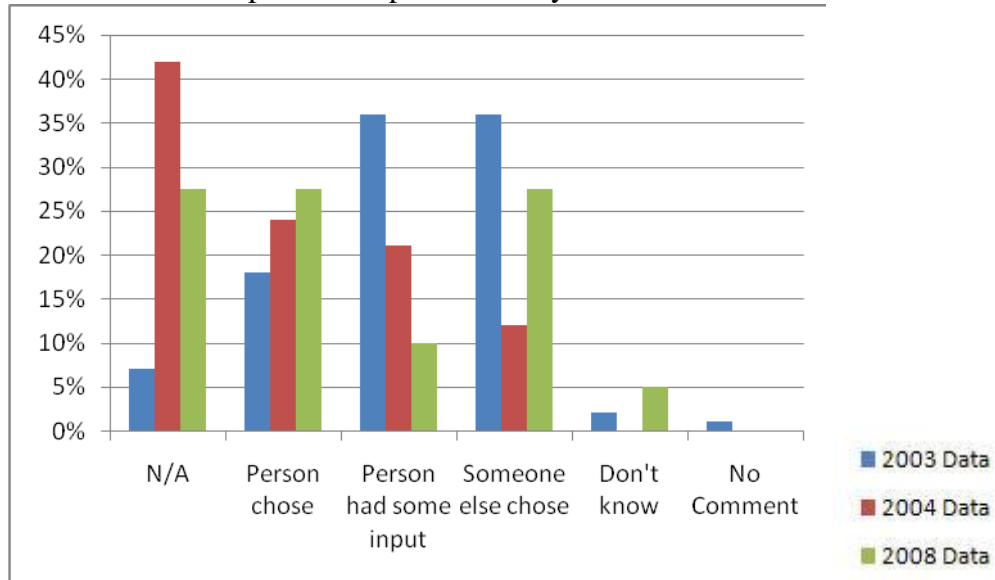
37. Do you go to clubs or other community meetings?



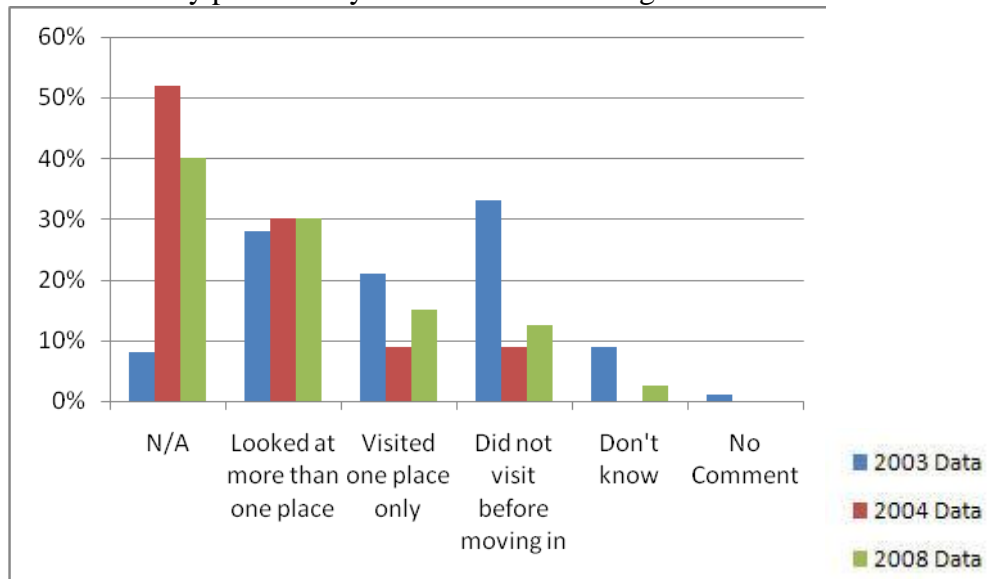
38. Do you exercise or play sports?



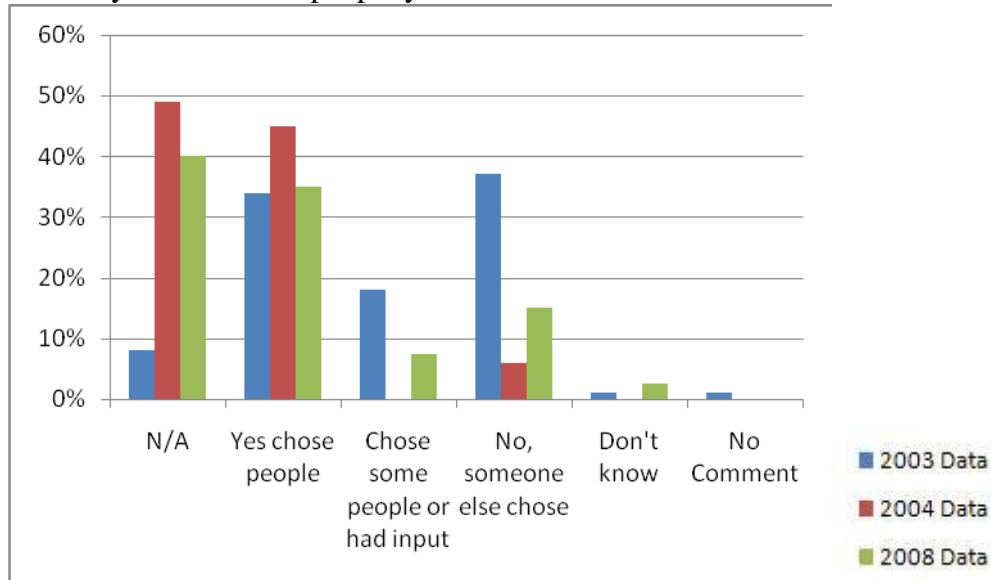
### 39. Who chose or picked the place where you live?



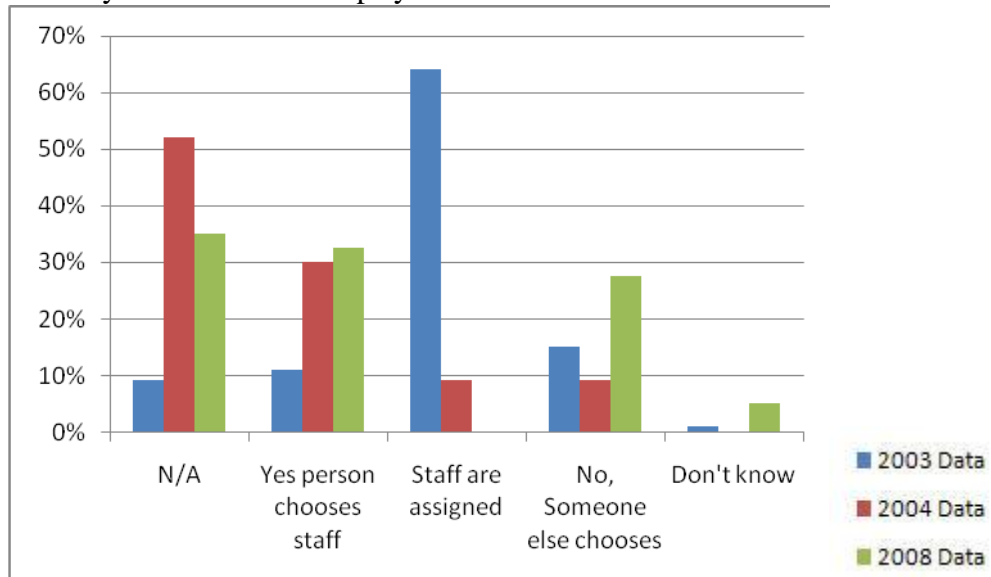
### 40. How many places did you visit before moving here?



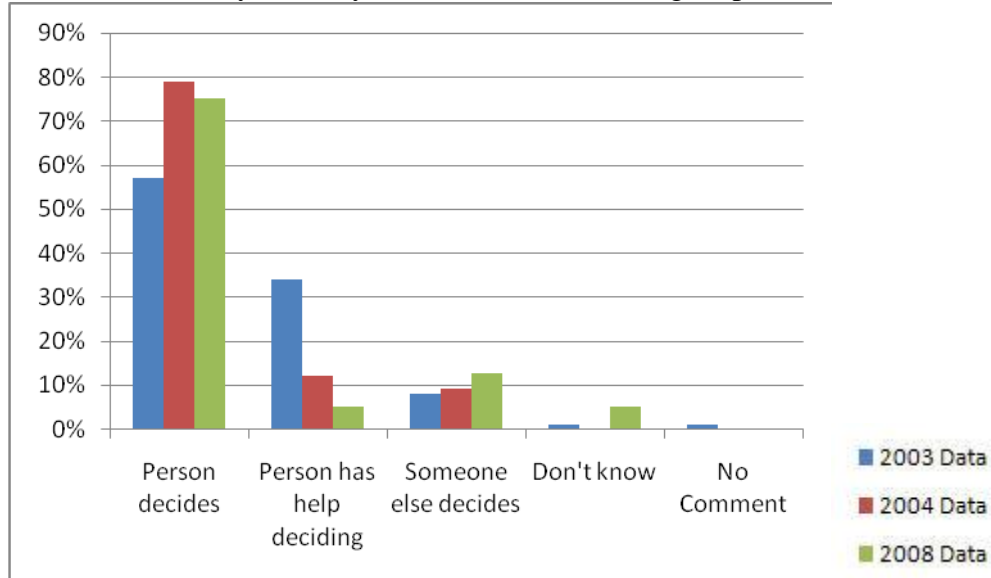
#### 41. Did you choose the people you live with?



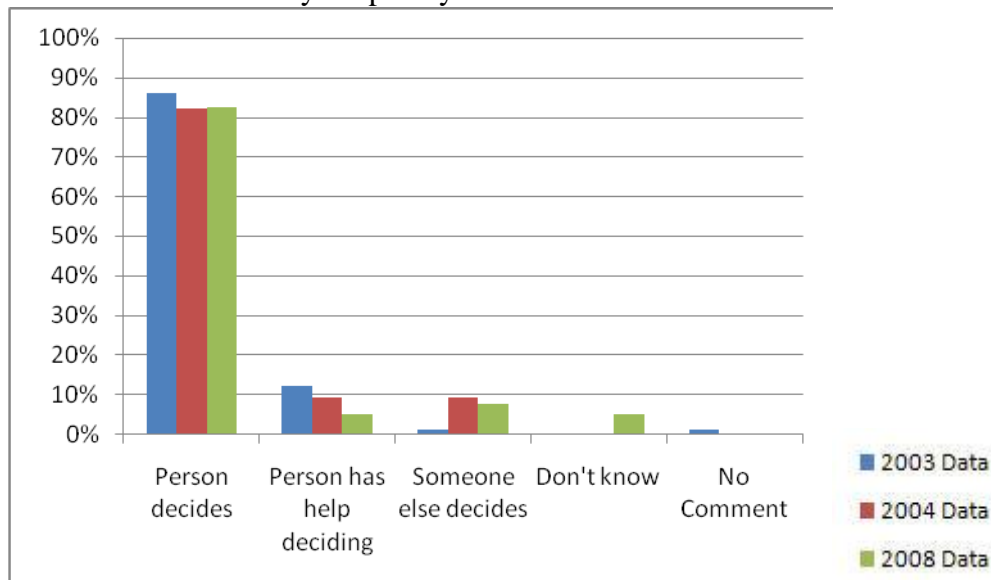
#### 43. Do you choose who helps you at home?



44. Who decides your daily schedule, like when to get up, when to eat, when to go to sleep?

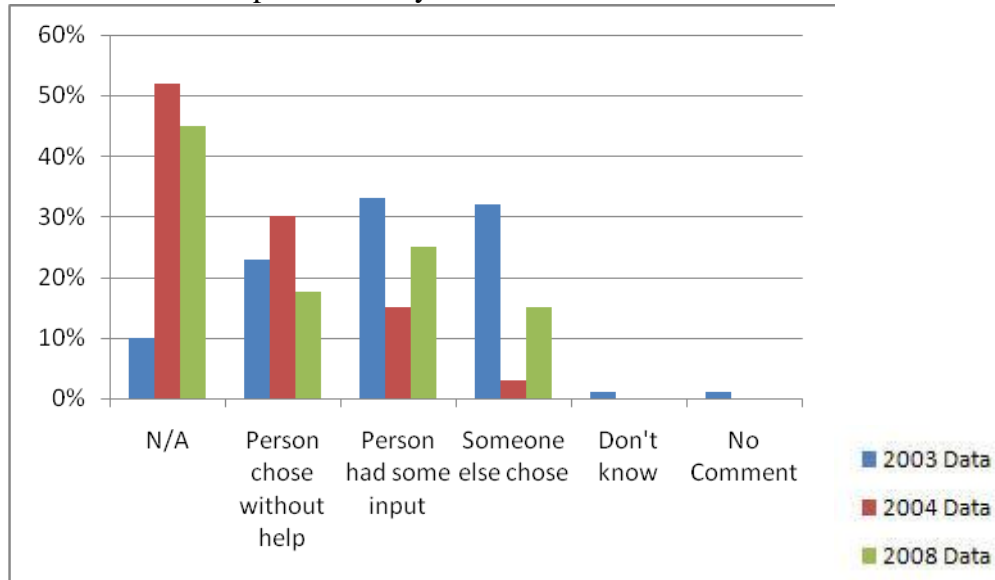


45. Who decides how you spend your free time?

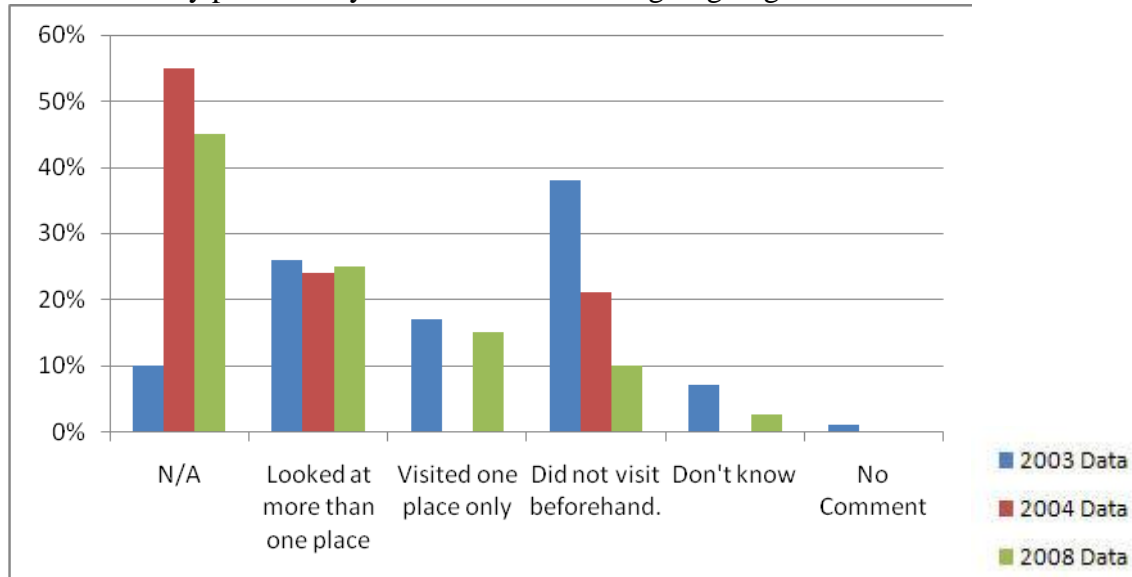




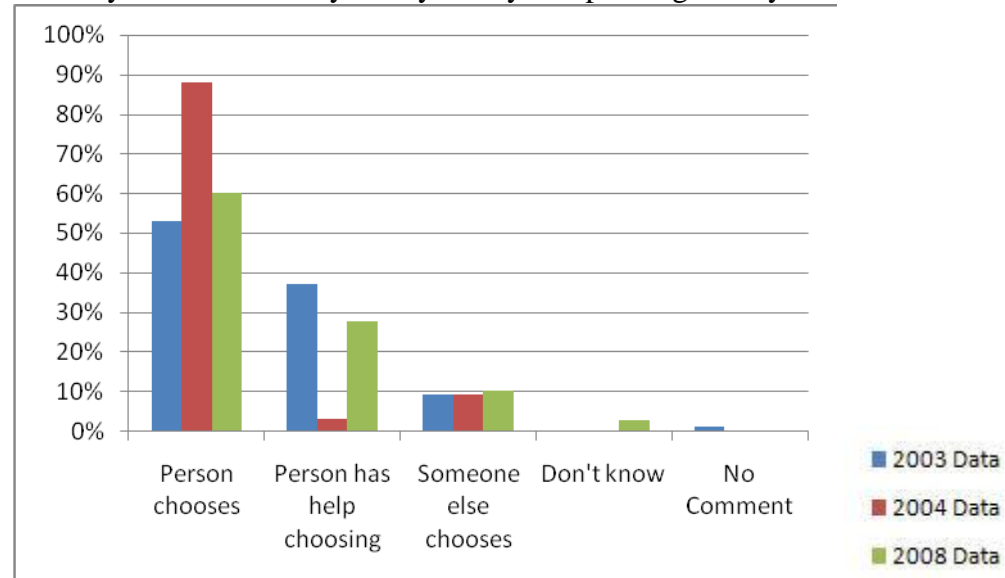
46. Who chose the place where you work?



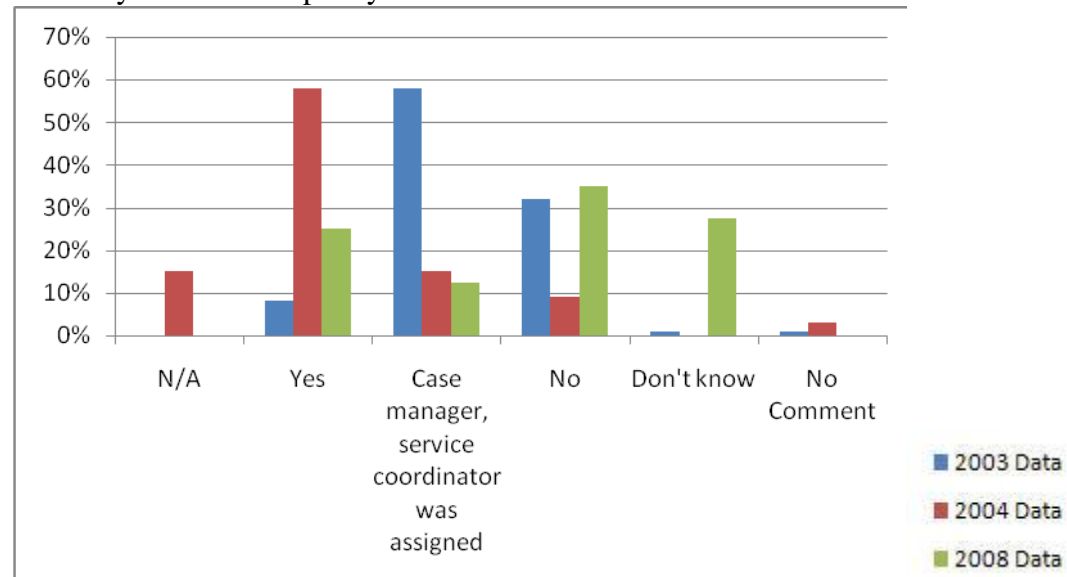
47. How many places did you visit before working or going there?



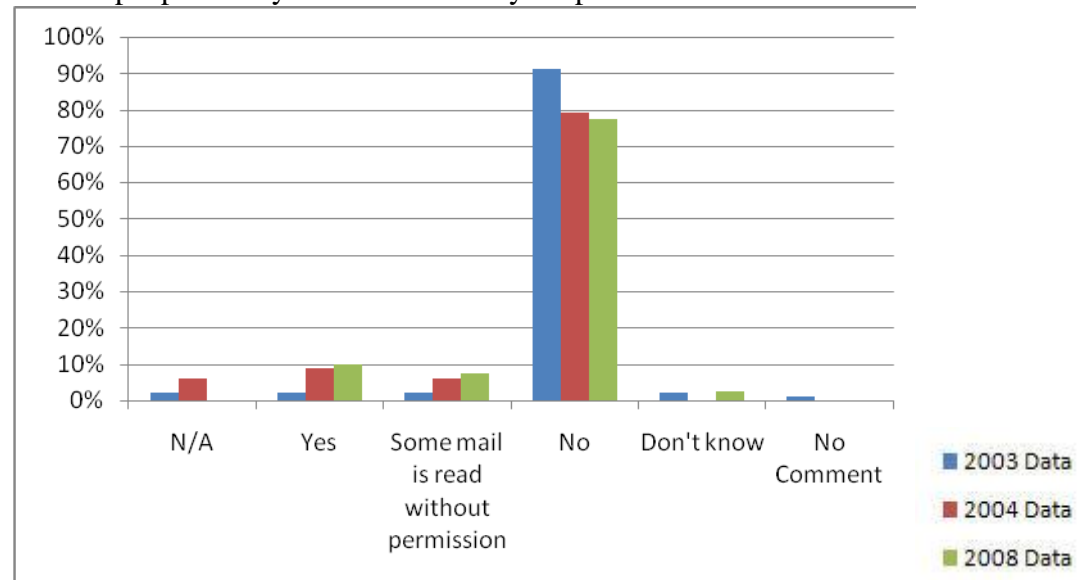
48. Do you choose what you buy with your spending money?



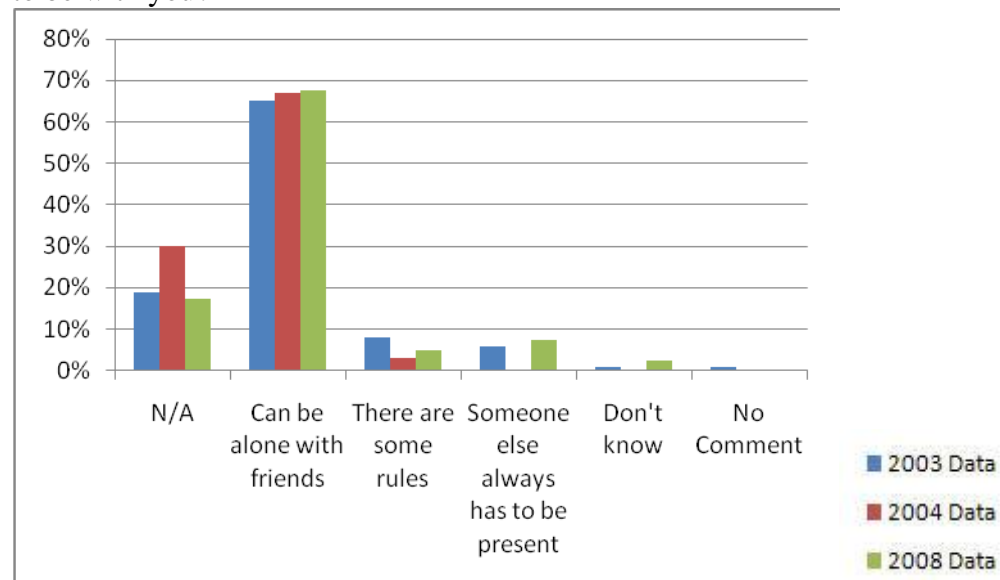
49. Did you choose or pick your coordinator?



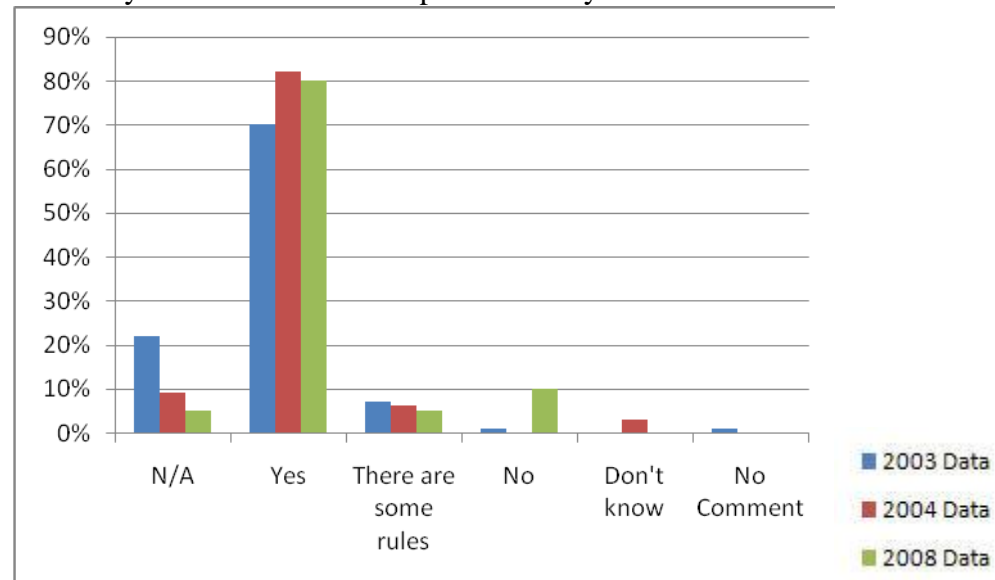
50. Do people read your mail without your permission?



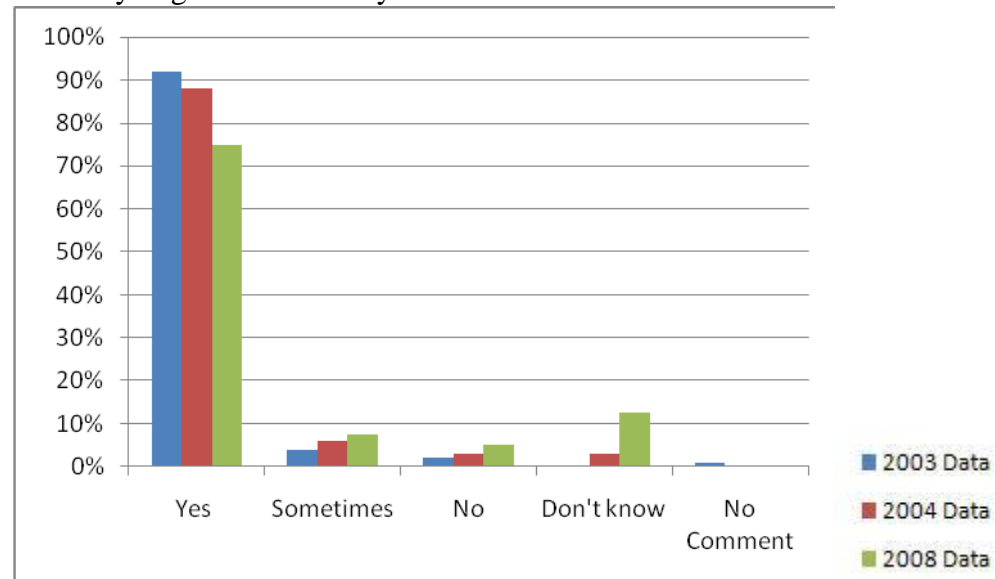
51. Do your friends ever come over to visit? Can you be alone with them, or does someone have to be with you?



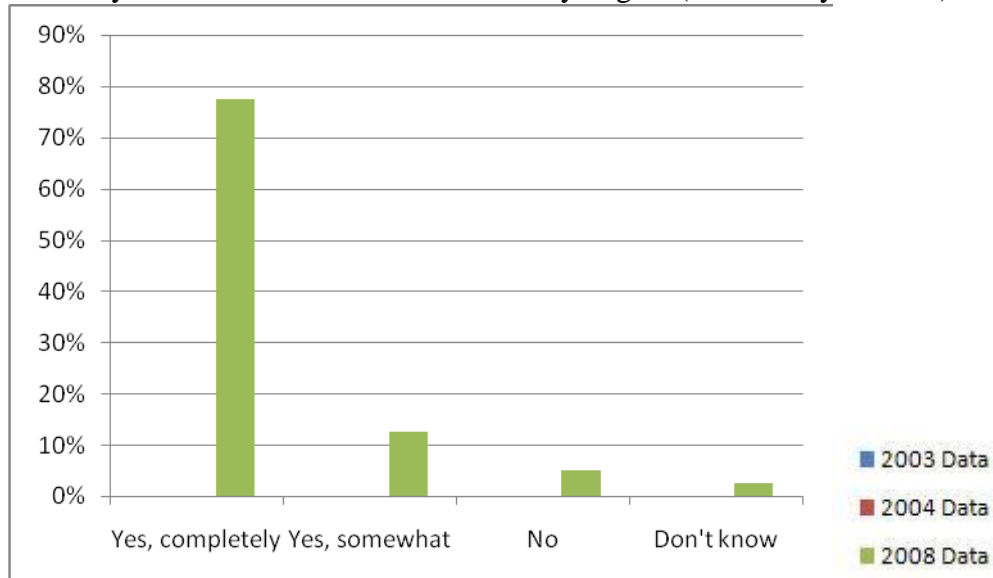
52. Are you allowed to use the phone when you want to?



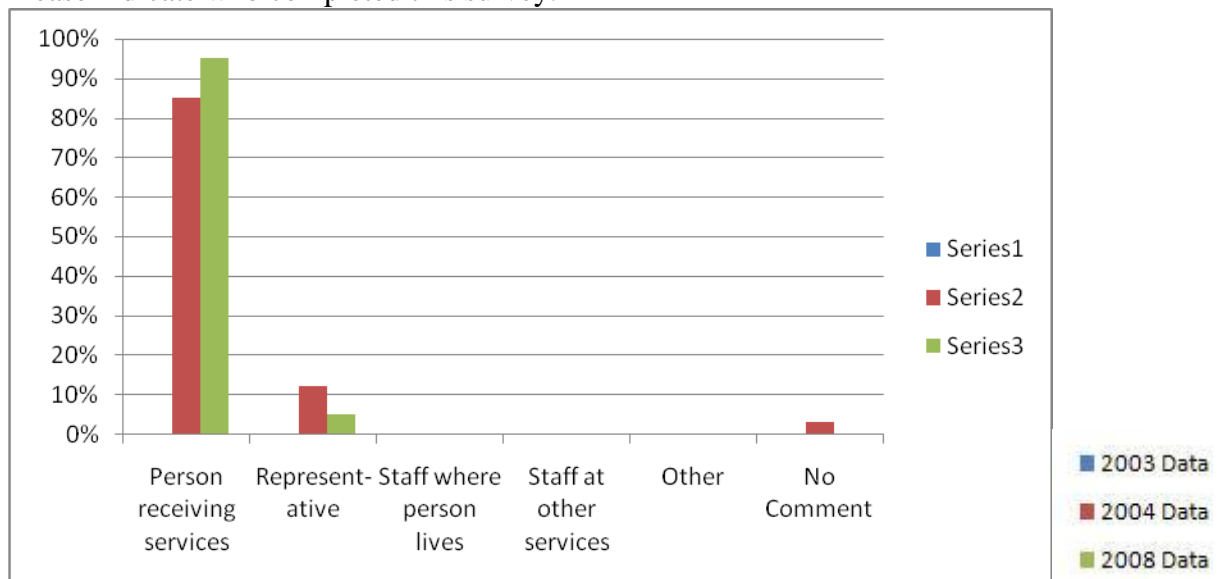
53. Do you get the services you need?



54. Are you satisfied with the services that you get? (Asked only in 2008)



Please indicate who completed this survey.



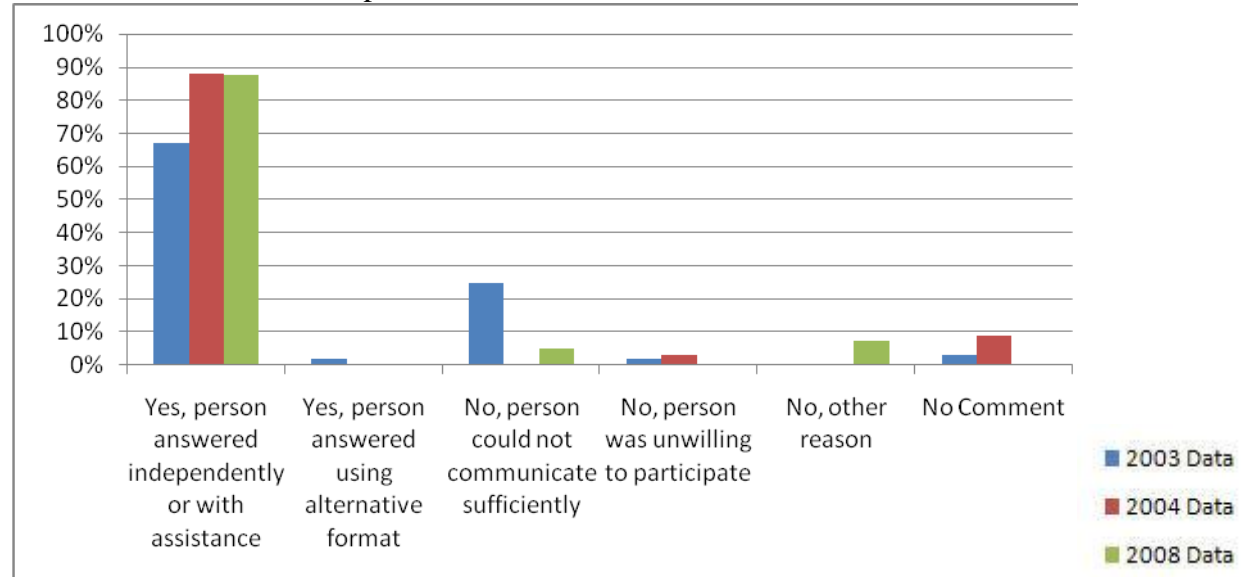
## Appendix D

### Complete results of goal one questions

Seventeen questions were targeted to the first goal, help people make their own choices. Fifty-three percent of responses to this group of questions indicated that participants do feel as if they make their own choices in areas such as choosing helpers, housing, personal schedule, and how personal money is spent. The number in parenthesis above each chart indicates the percentage of affirmative responses in 2008.

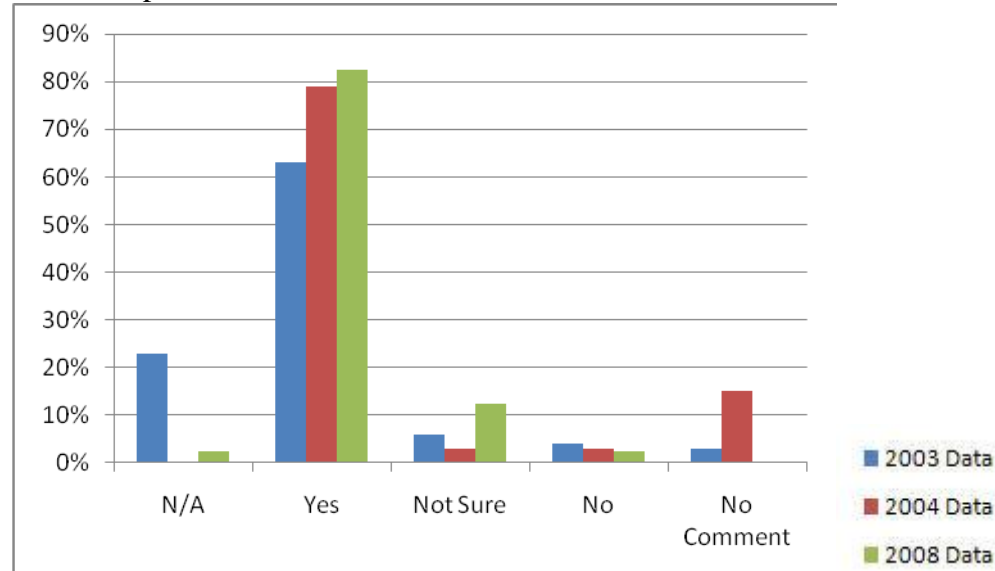
(87.5%)

29. Could section I be completed?



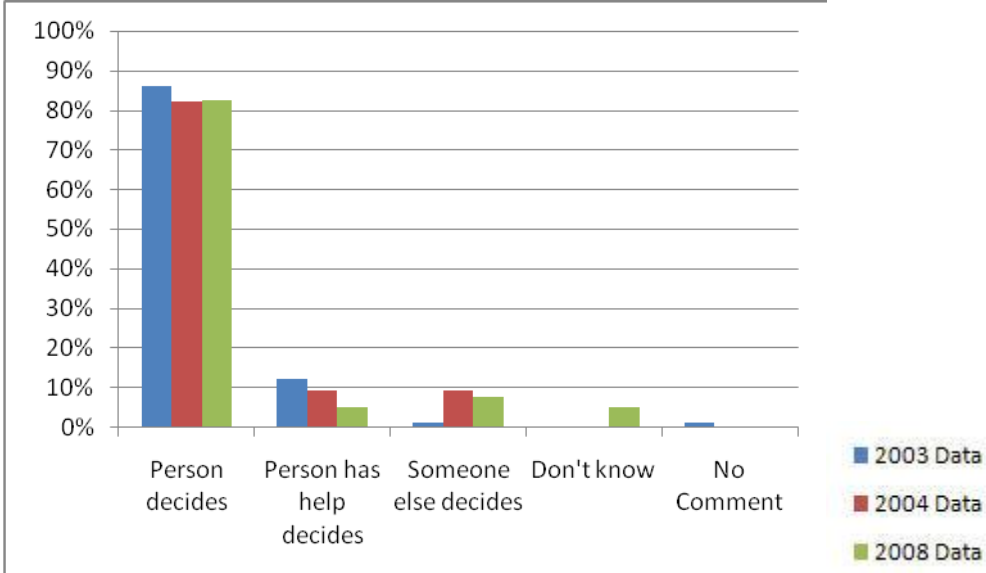
(82.5%)

31. In your opinion, did the individual answer the questions in a consistent manner? Do you feel his/her responses were valid?



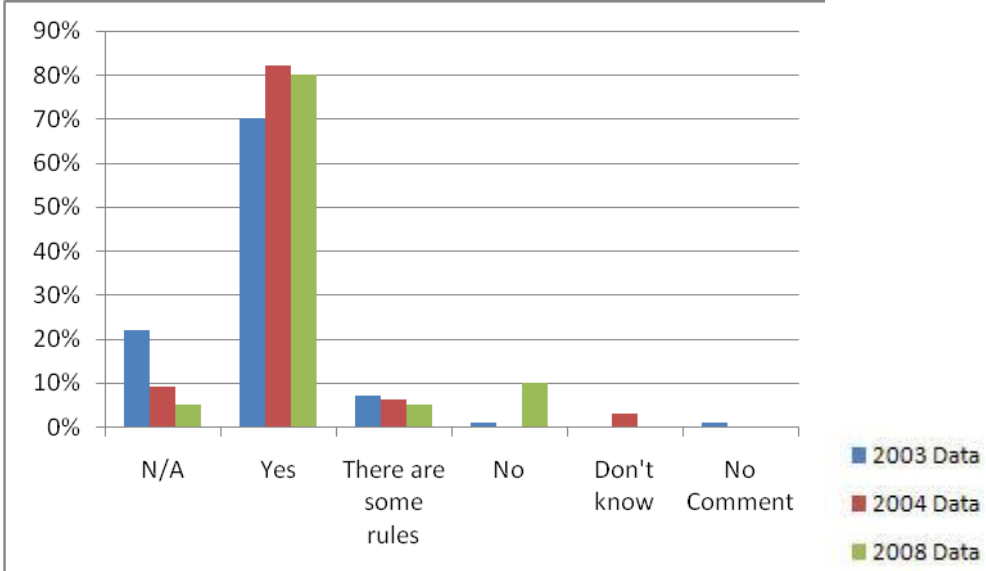
(82.5%)

45. Who decides how you spend your free time?



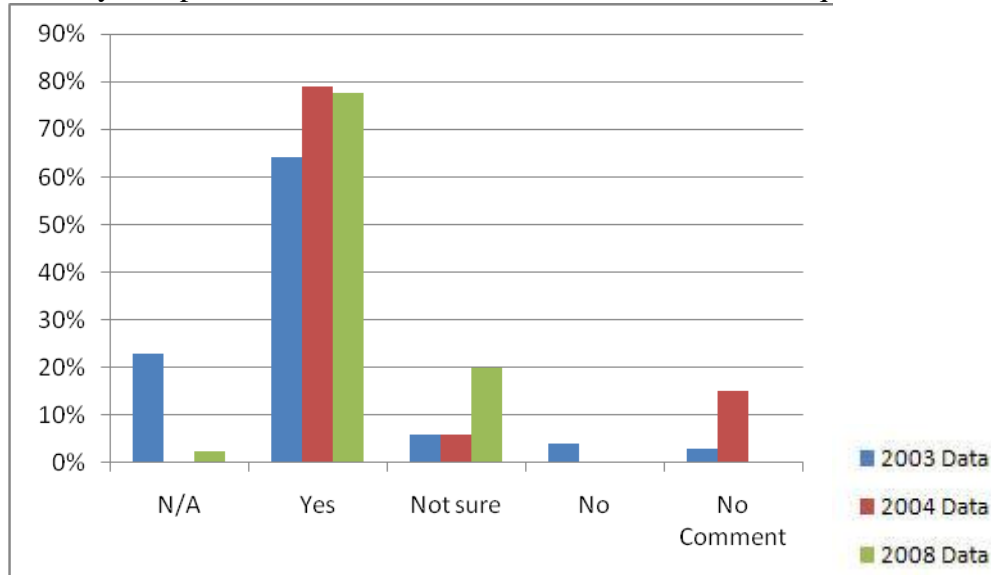
(80%)

52. Are you allowed to use the phone when you want to?



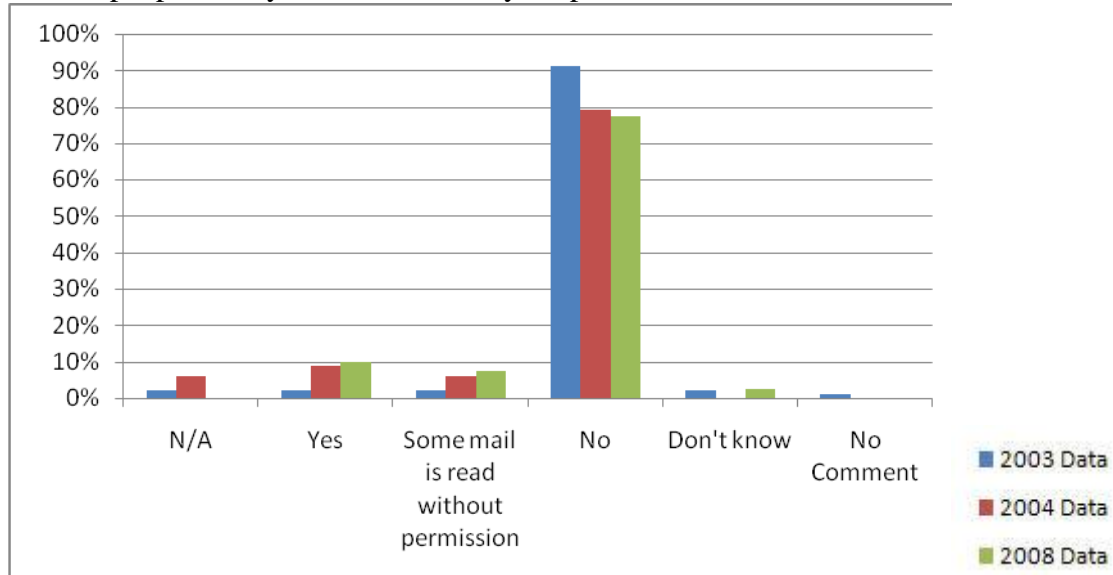
(77.5%)

30. In your opinion, did the individual understand most of the questions or not?



Recoded (77.5%)

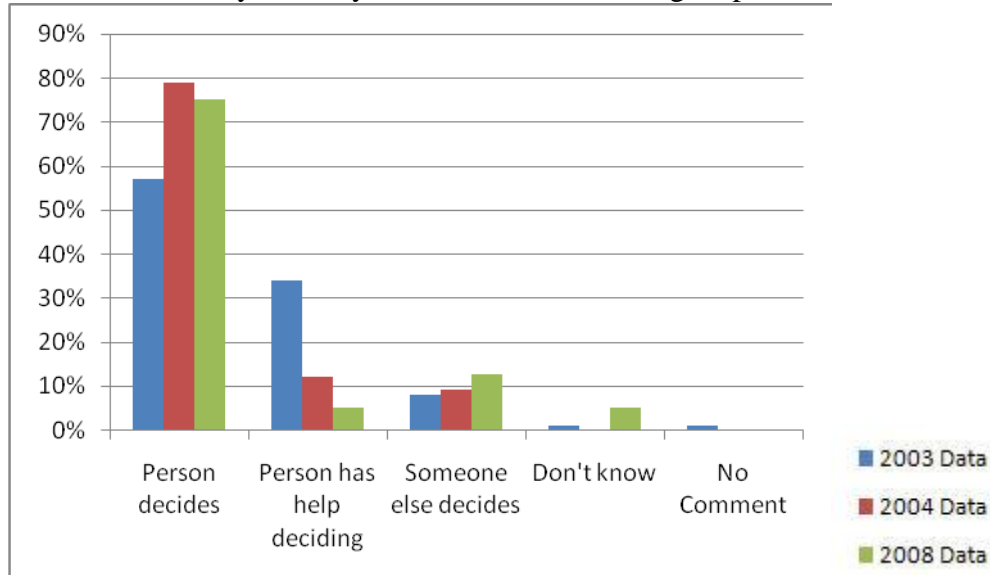
50. Do people read your mail without your permission?





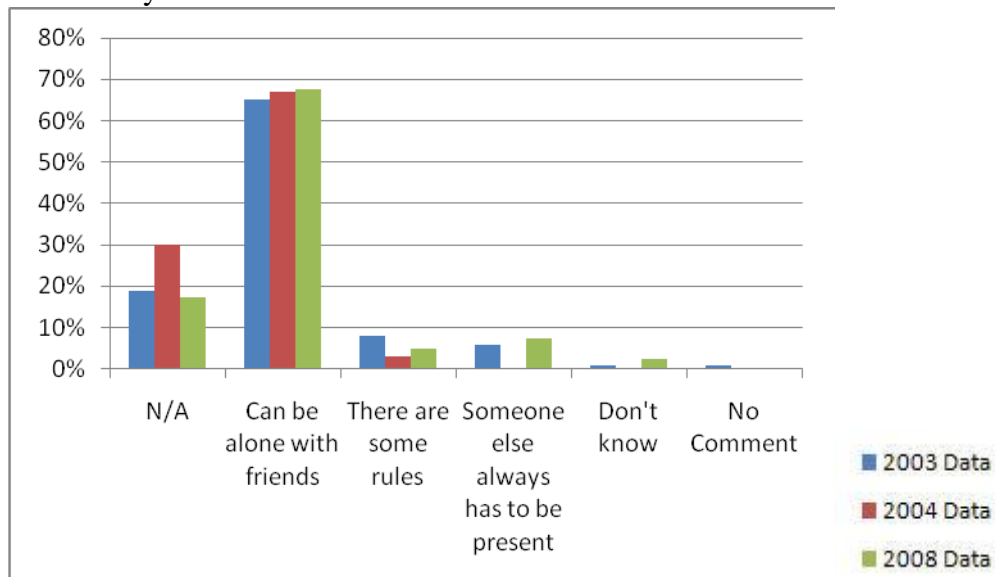
(75%)

44. Who decides your daily schedule, like when to get up, when to eat, when to go to sleep?



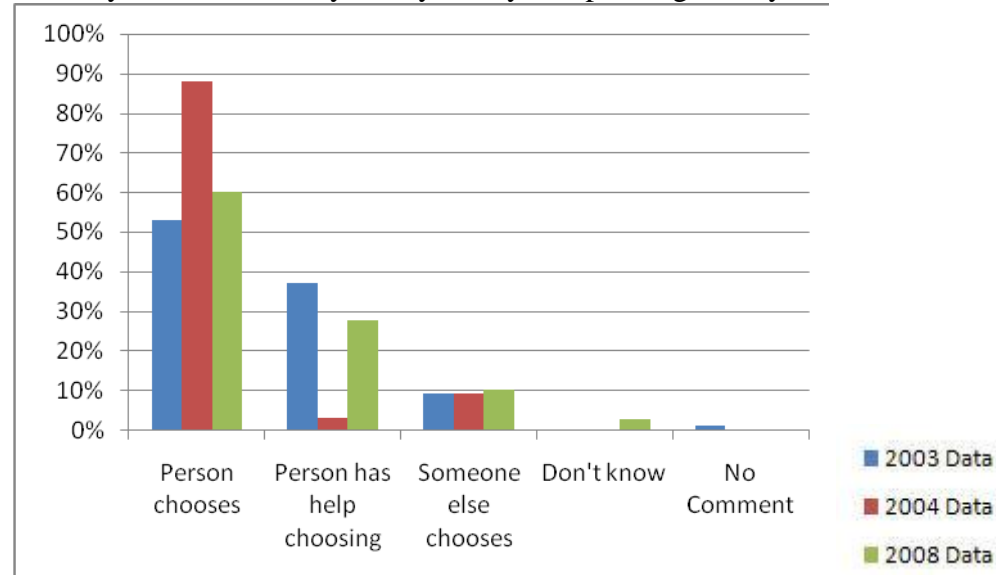
(67%)

51. Do your friends ever come over to visit? Can you be alone with them, or does someone have to be with you?



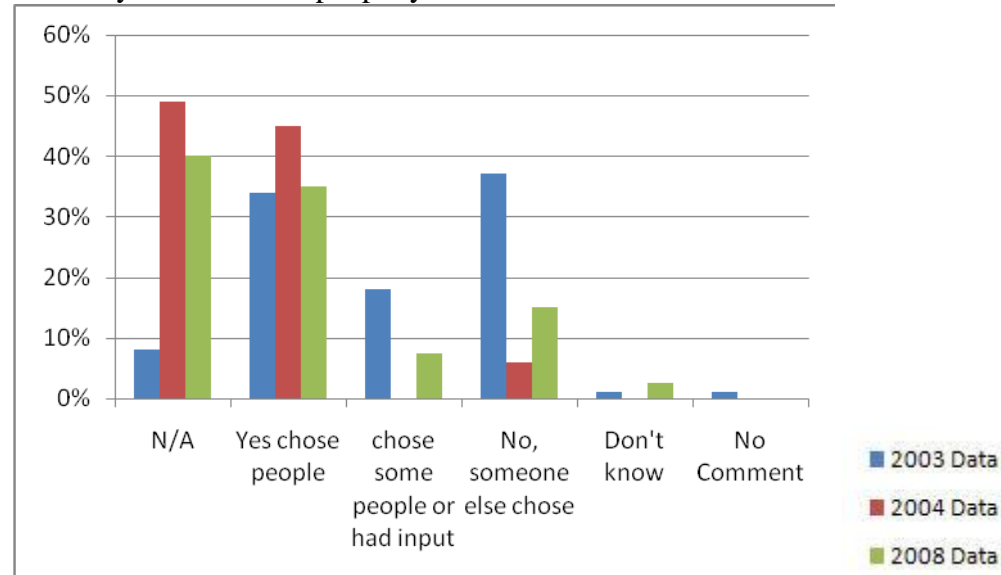
(60%)

48. Do you choose what you buy with your spending money?



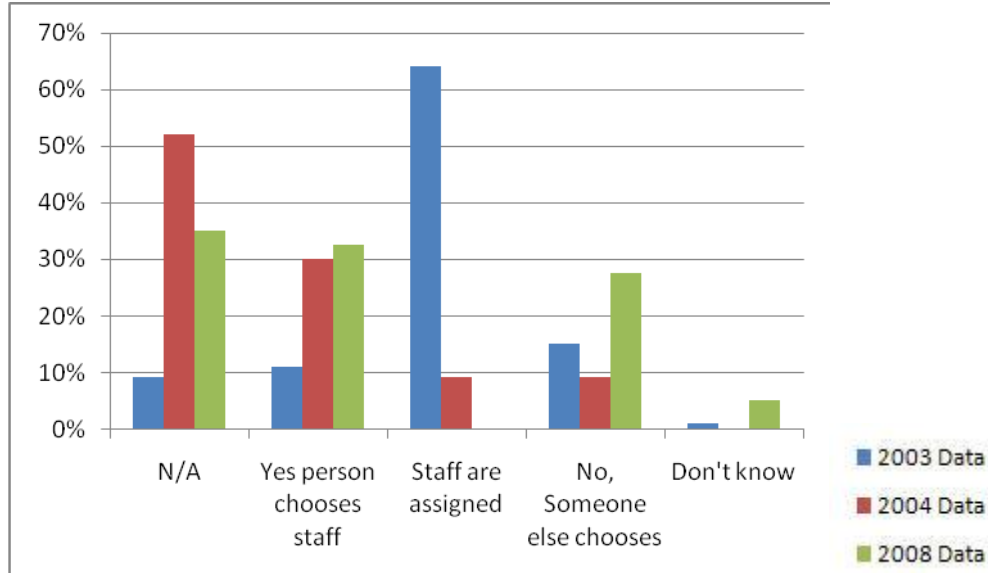
(35%)

41. Did you choose the people you live with?



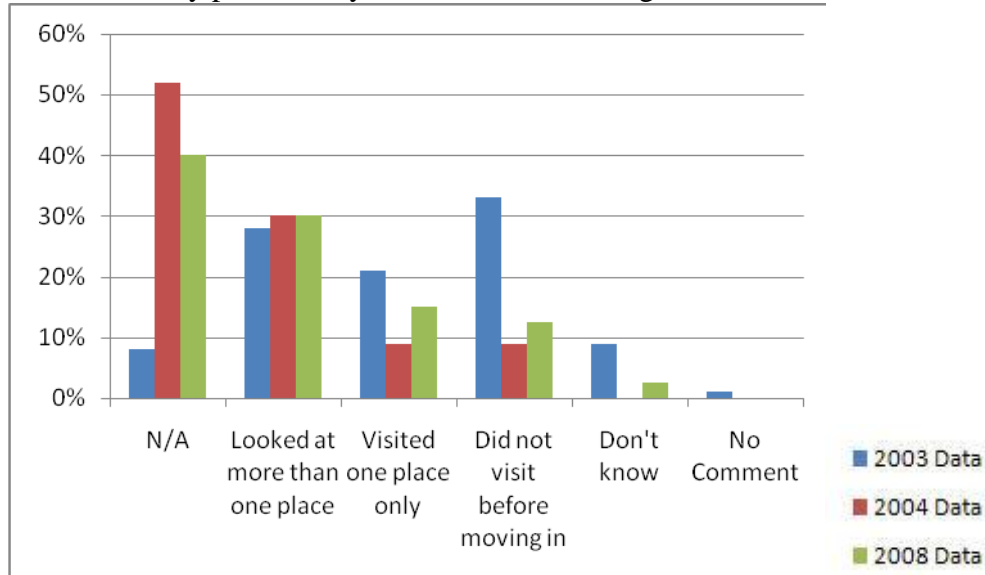
(32.5%)

43. Do you choose who helps you at home?



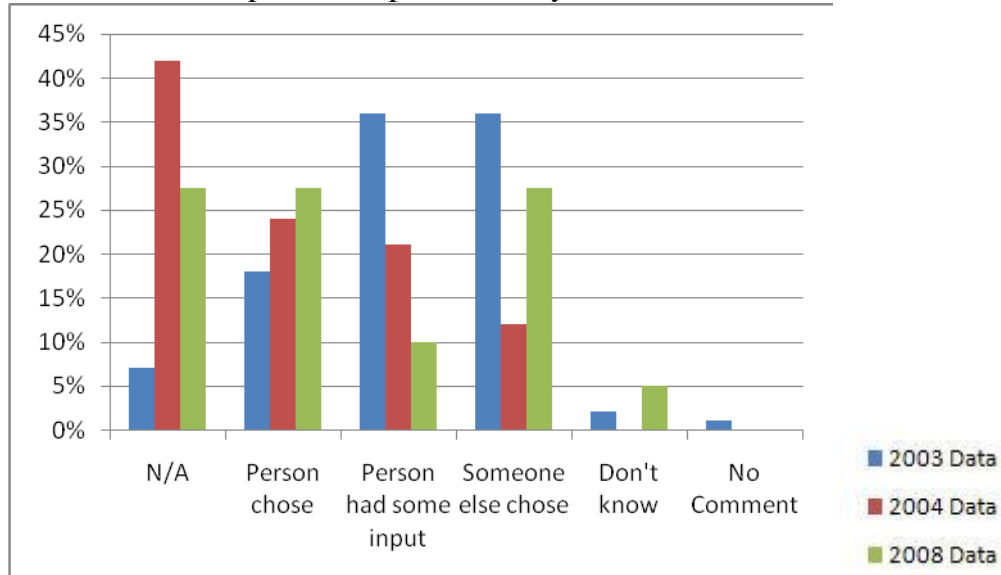
(30% looked at more than one)

40. How many places did you visit before moving here?



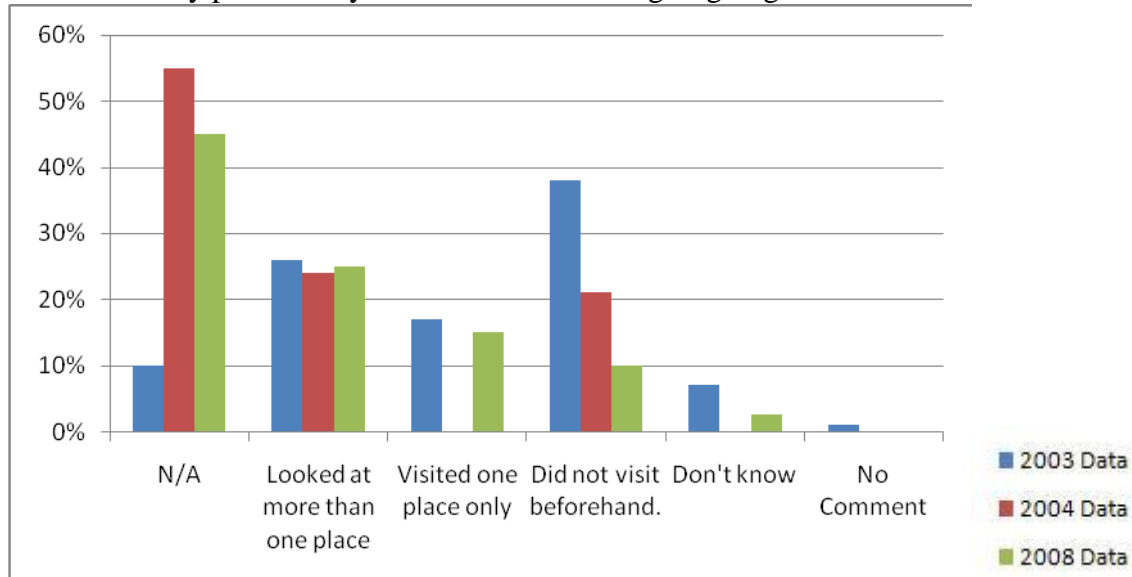
(27.5%)

39. Who chose or picked the place where you live?



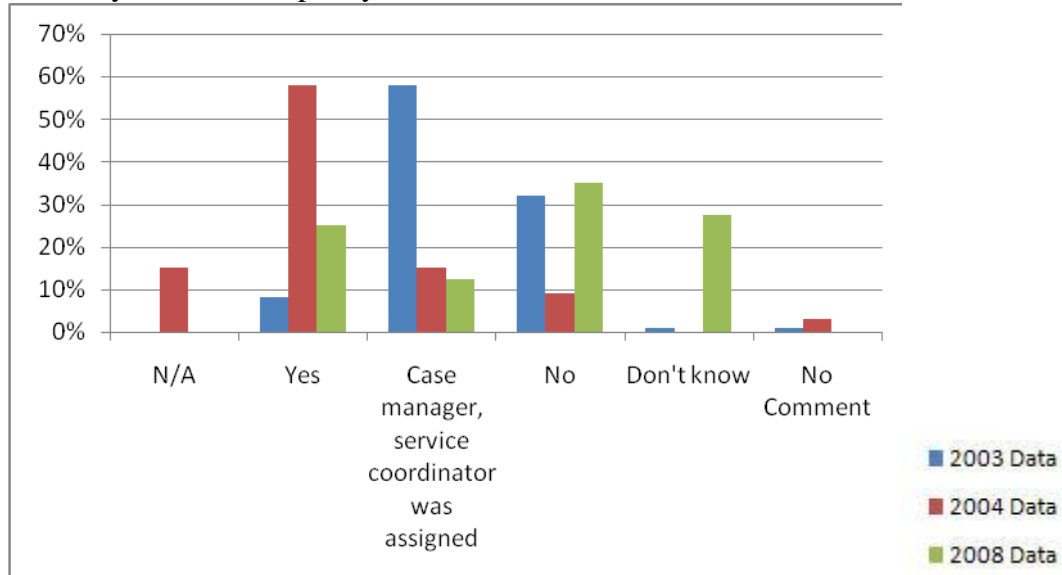
(25%)

47. How many places did you visit before working or going there?



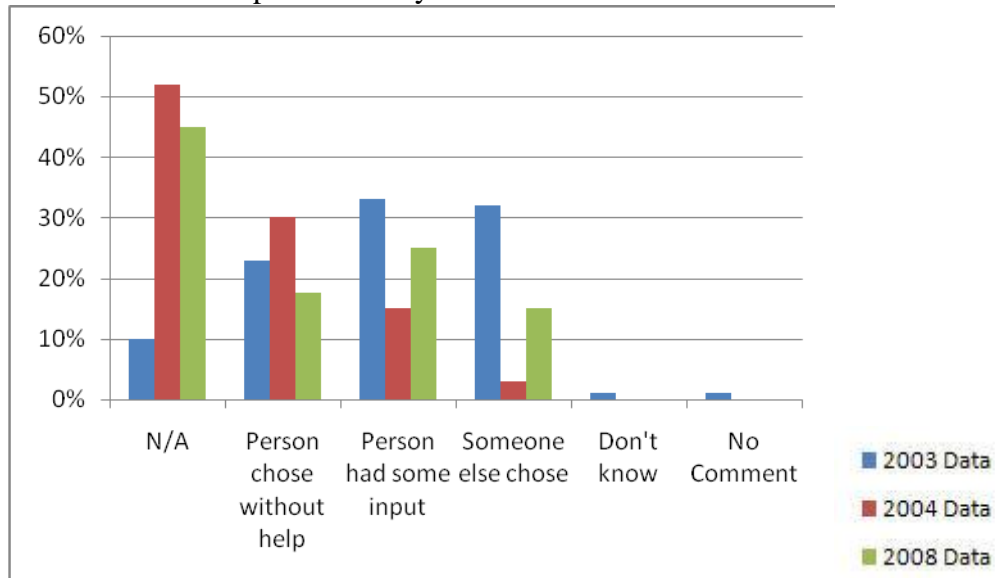
(25%)

49. Did you choose or pick your coordinator?



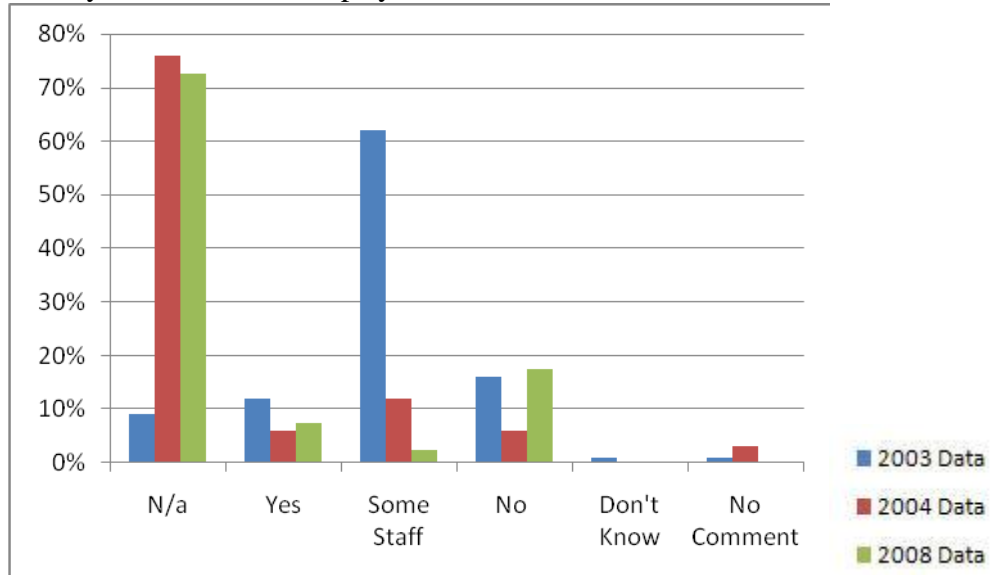
(17.5%)

46. Who chose the place where you work?



7.5%

3. Do you choose who helps you at work?



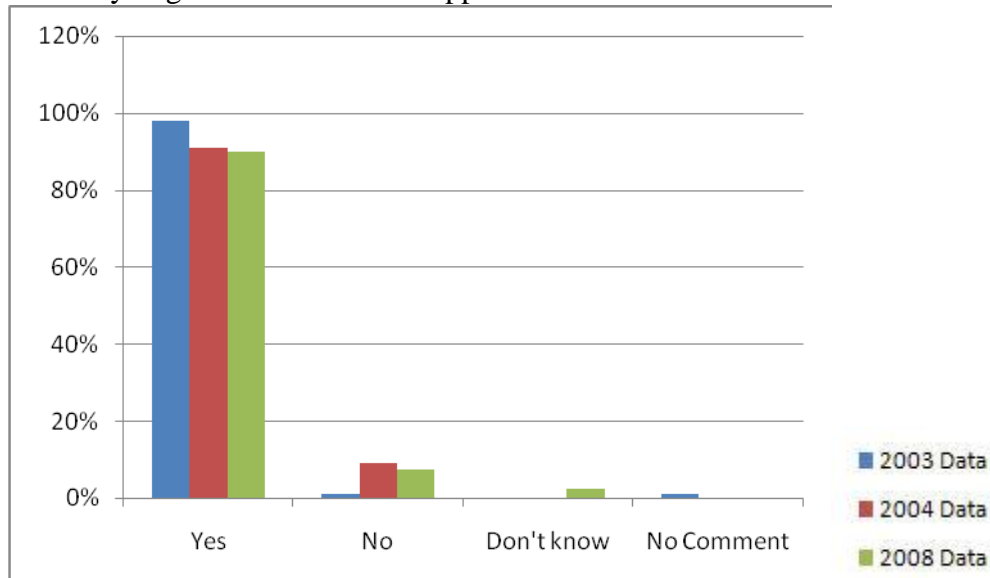
## Appendix E

### Complete results of goal two questions

Sixteen questions were targeted to the second goal, help people live and work in their community. These responses indicated that sixty-five percent of respondents do see themselves interacting in the community. The number in parenthesis above each chart indicates the percentage of affirmative responses in 2008.

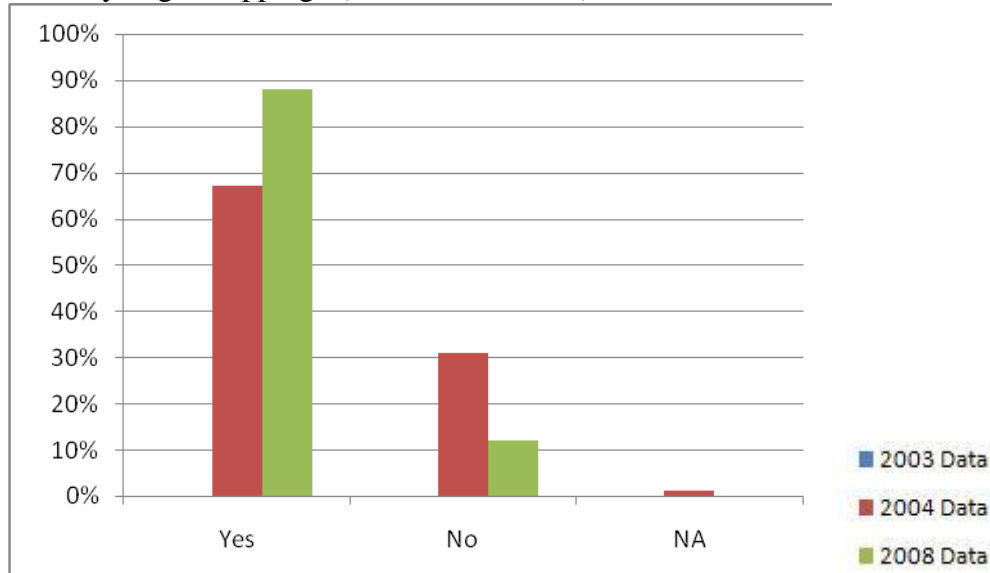
(91%)

33. Do you go out on errands or appointments?



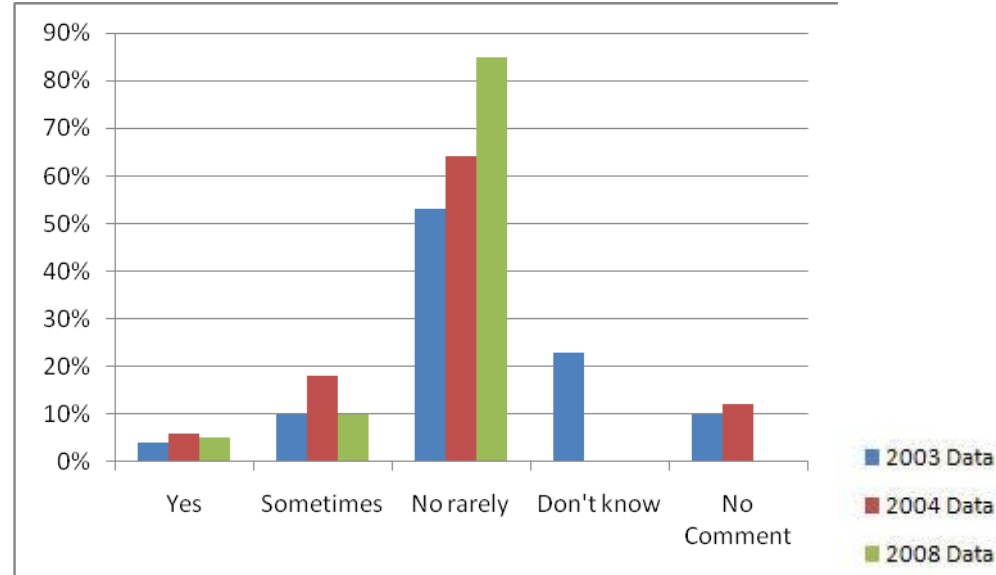
(87.5%)

32. Do you go shopping? (Not asked in 2003)



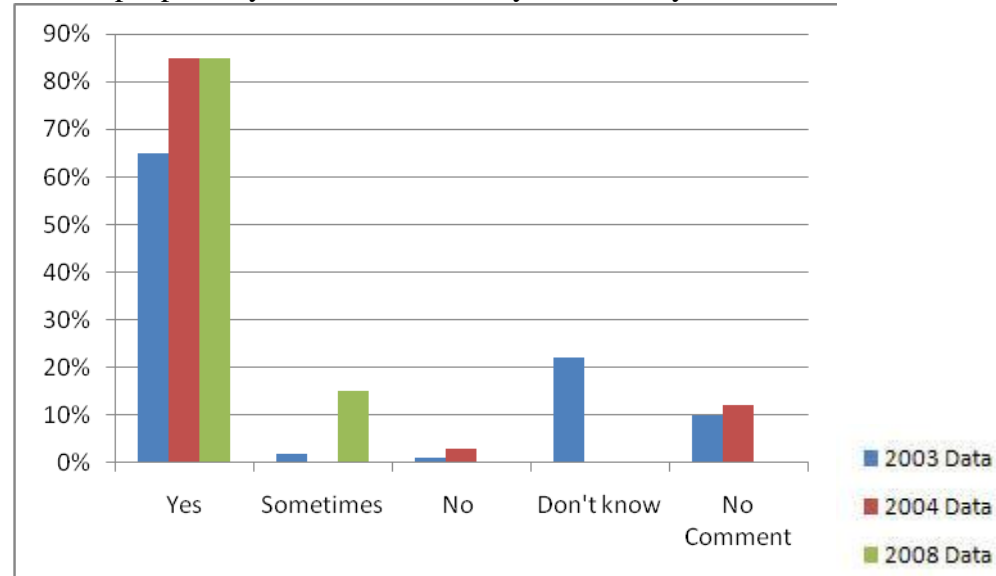
(85%)

7. Are you ever afraid or scared when you are at home?



(85%)

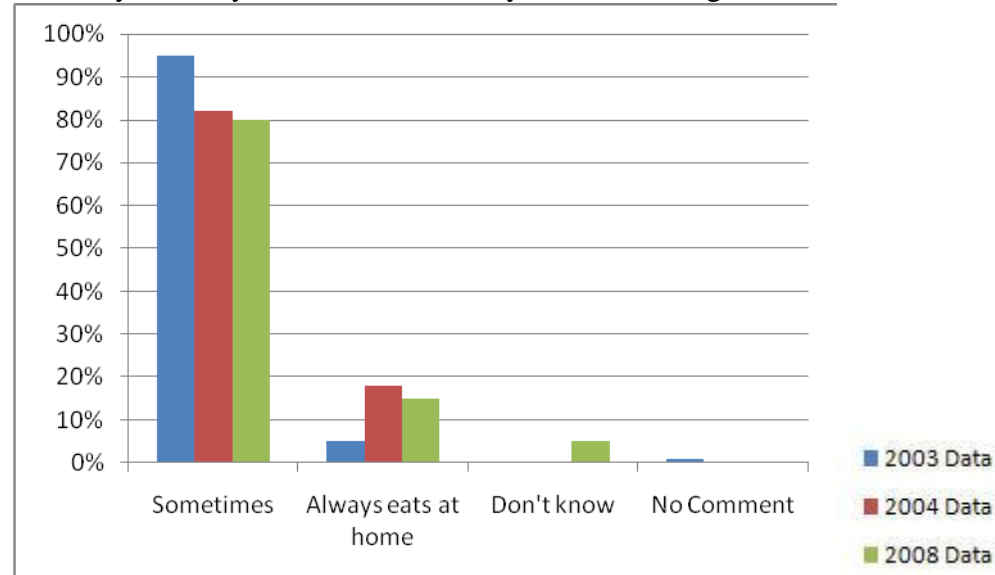
11. Do people let you know before they come into your home?





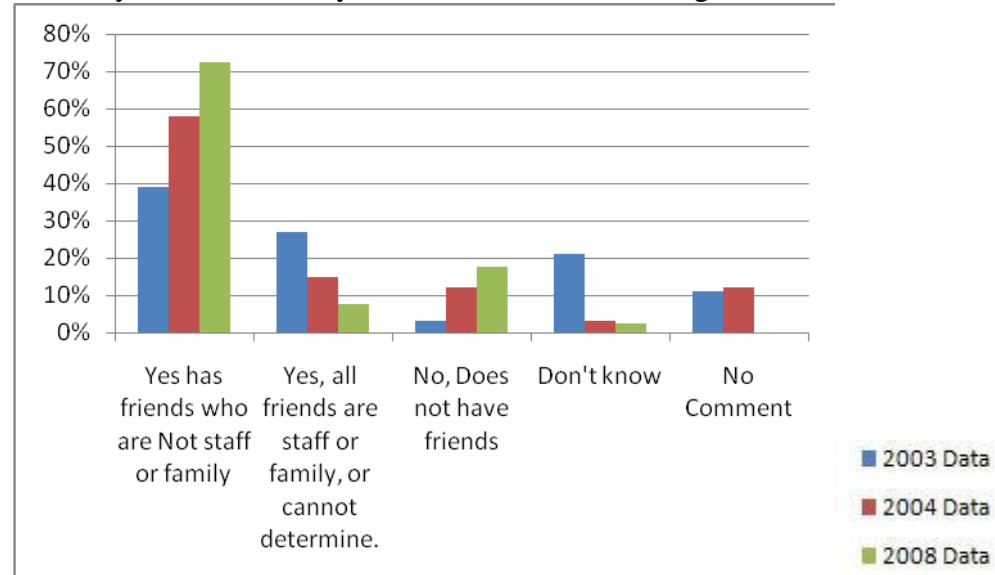
(80%)

35. Do you always eat at home, or do you sometimes go out to eat?



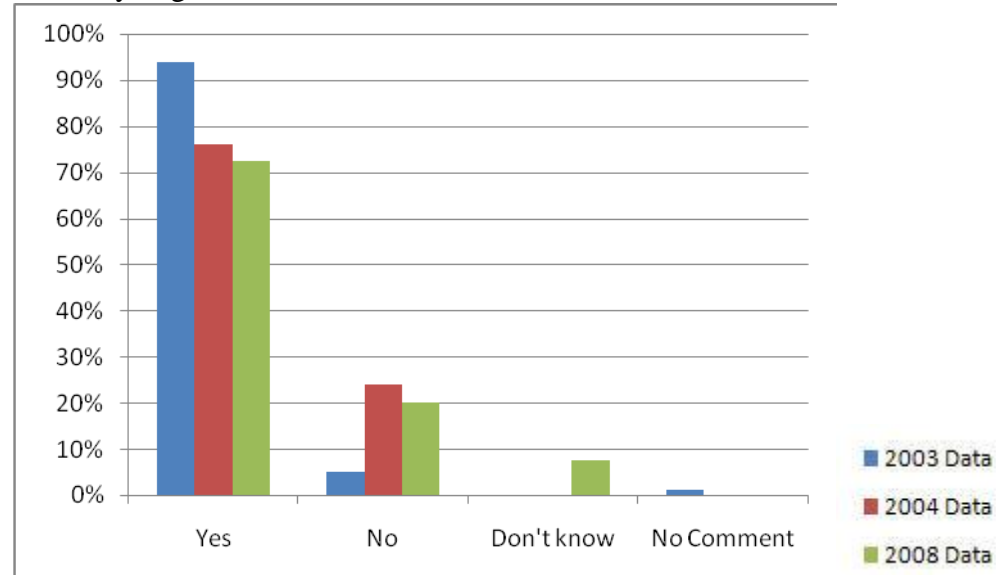
(72.5%)

13. Do you have friends you like to talk to or do things with?



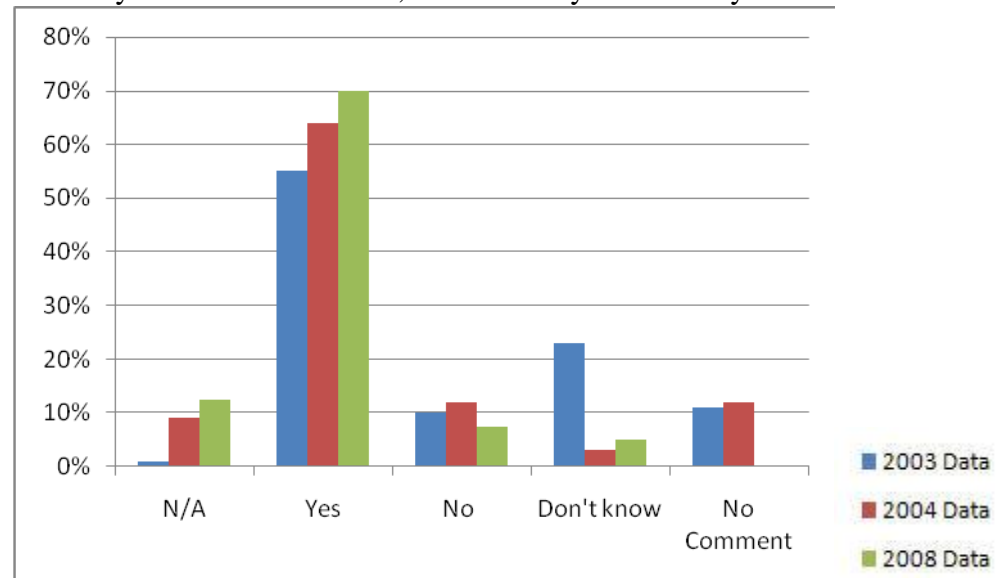
(72.5%)

34. Do you go out for entertainment?



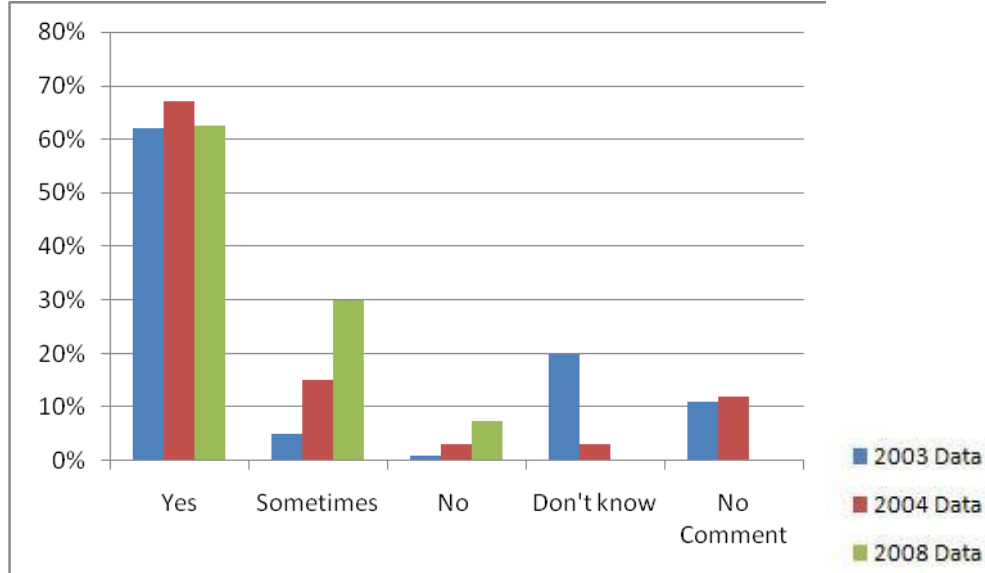
(70%)

14. Do you have a best friend, or someone you are really close to?



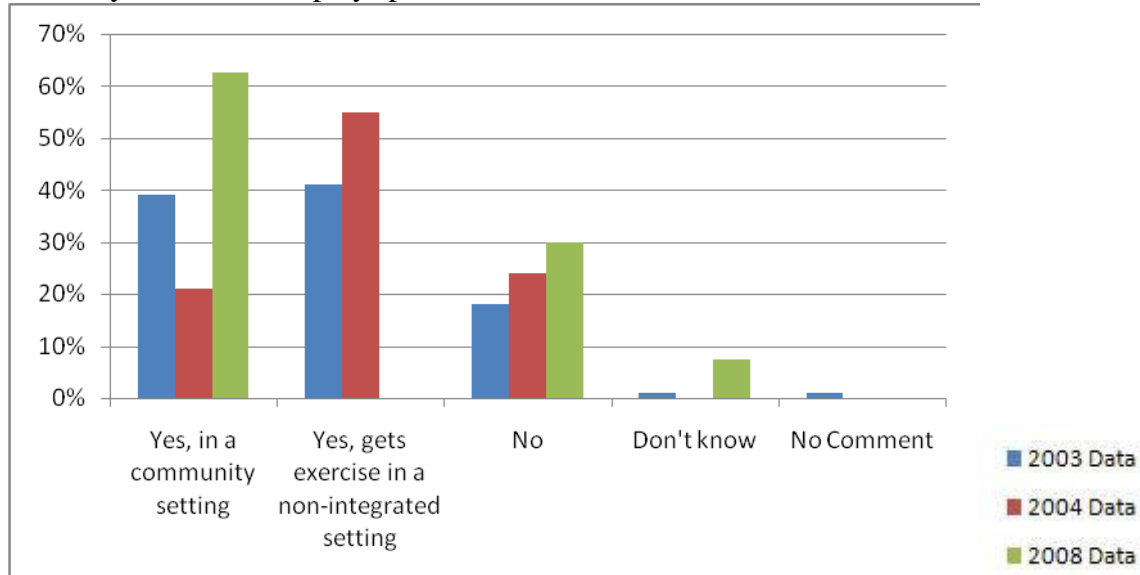
(62.5%)

26. When you want to go somewhere, do you always have a way to get there?



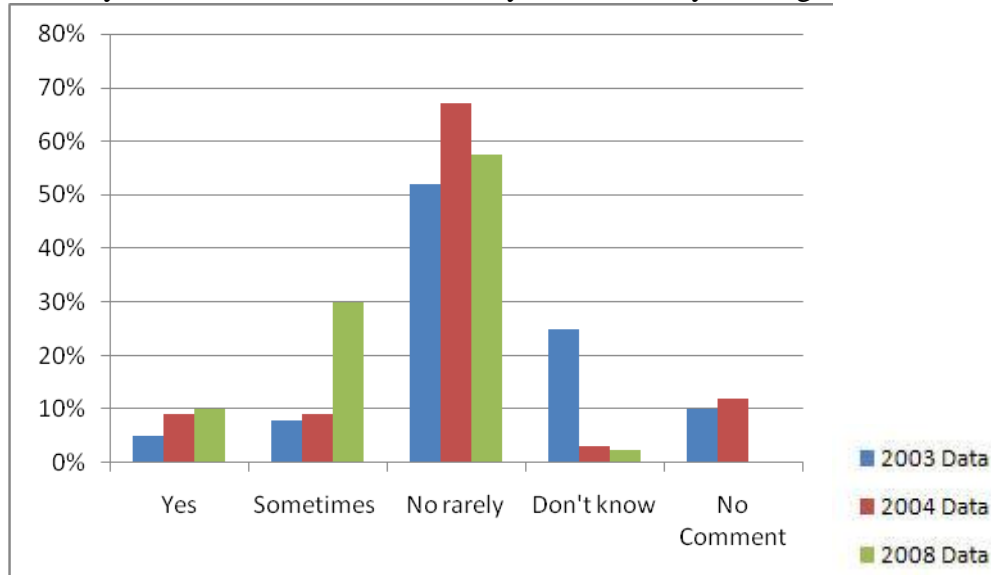
(62%)

38. Do you exercise or play sports?



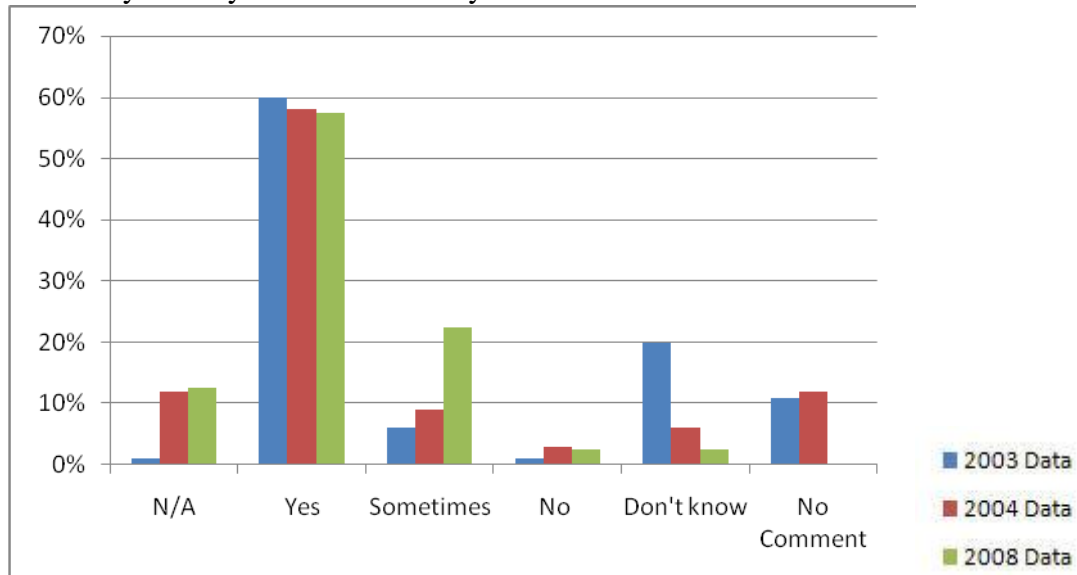
(57.5%)

8. Are you ever afraid or scared when you are out in your neighborhood?



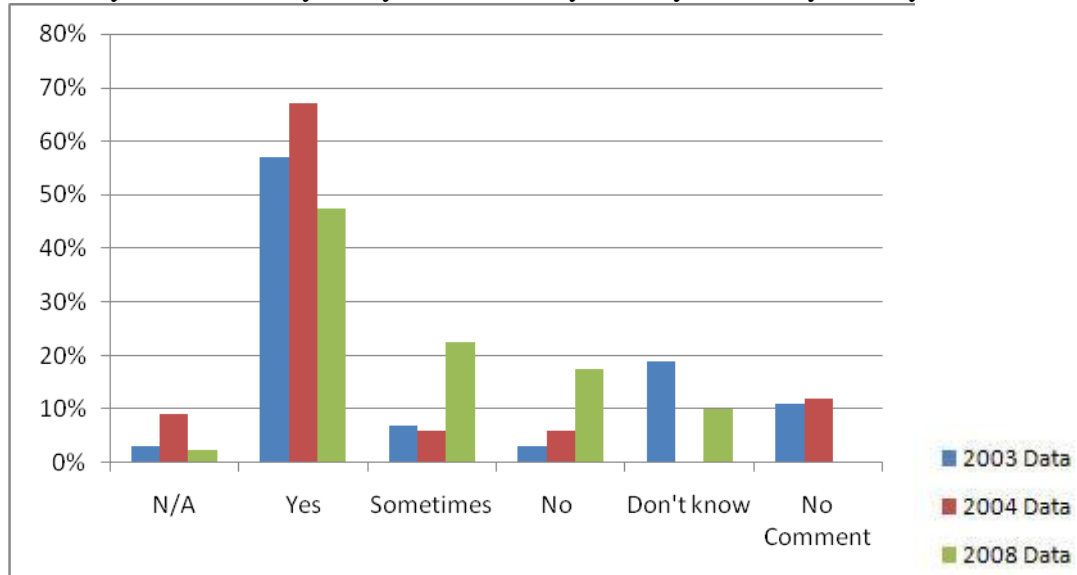
(57.5%)

15. Can you see your friends when you want to see them?



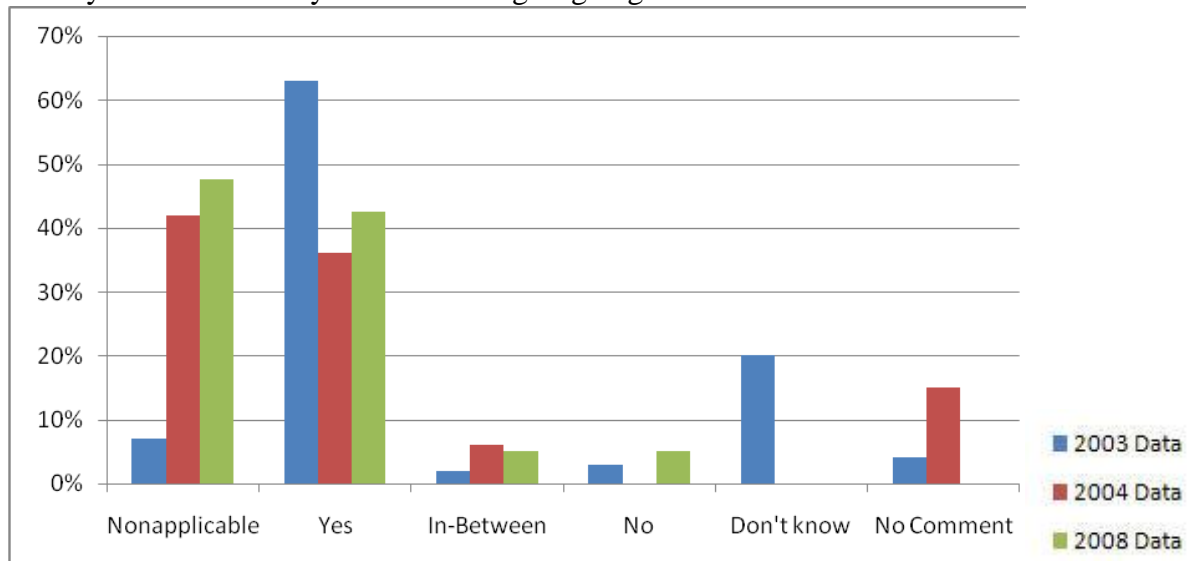
(47.5%)

18. Do you have family that you see? Can you see your family when you want to?



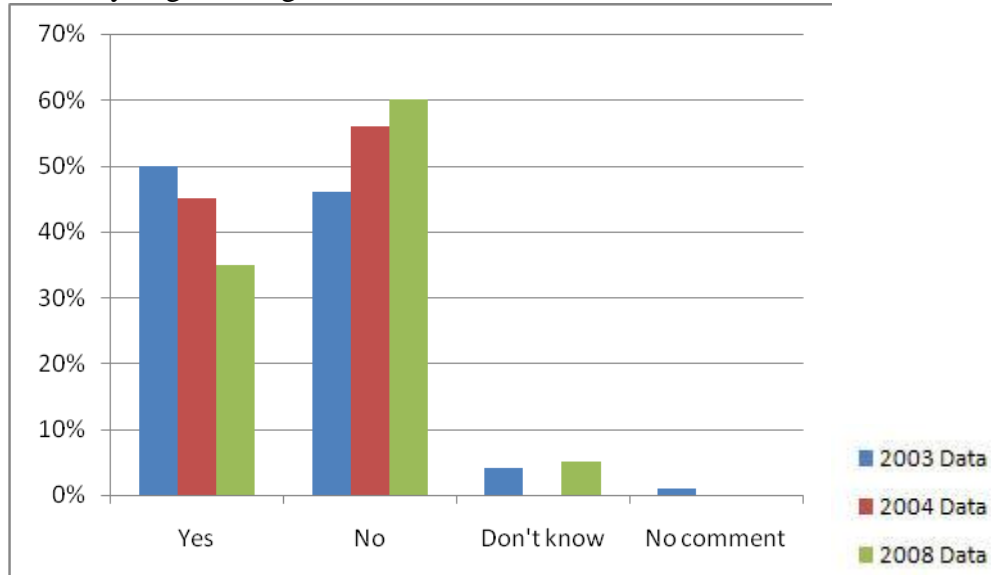
(47%)

1. Do you work and do you like working or going there?



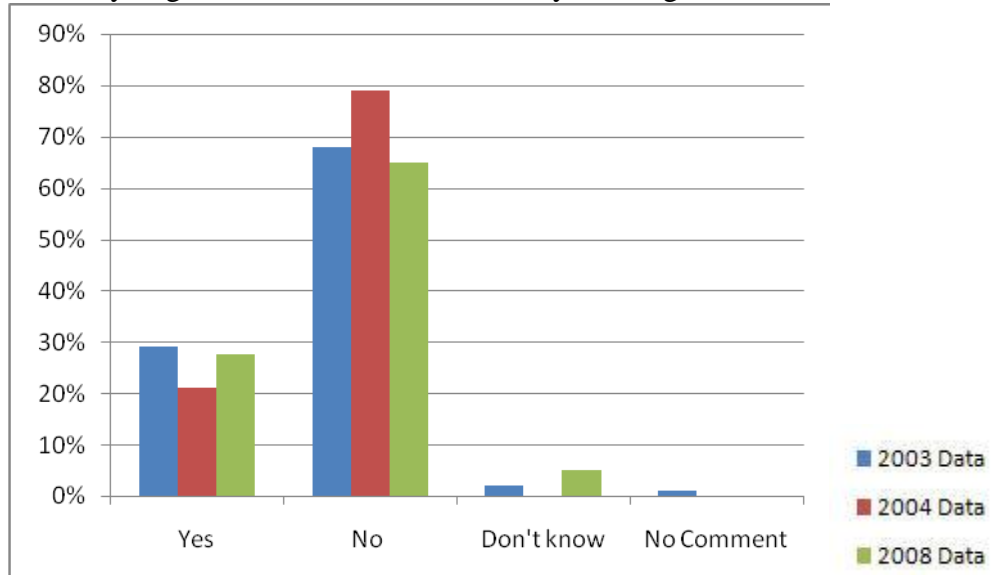
(35%)

36. Do you go to religious services?



(27.5%)

37. Do you go to clubs or other community meetings?



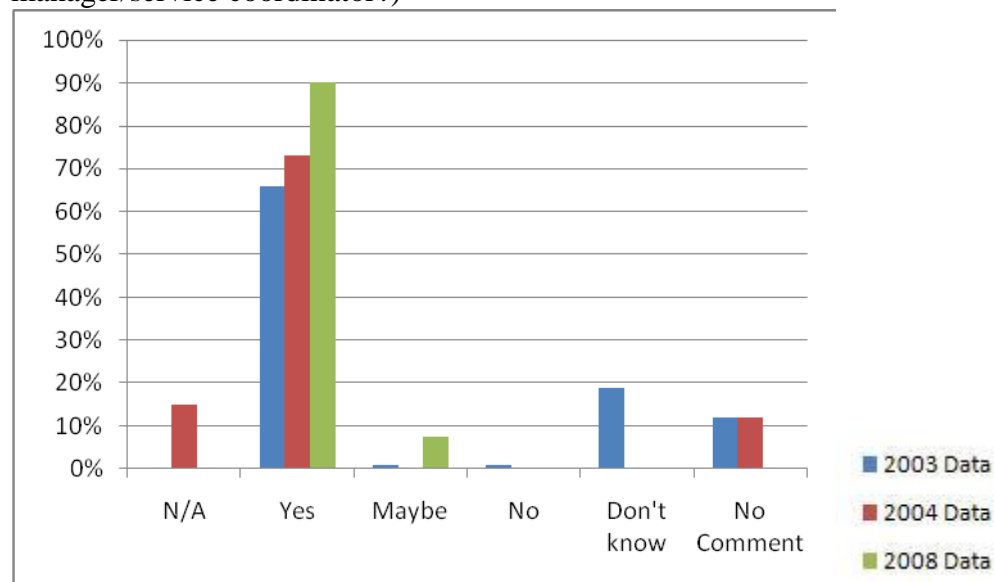
## Appendix F

### Complete results of goal three questions

Eleven questions were targeted to goal three, help people find the supports that they want in their community. An average of fifty-five percent of responses to these questions indicate that participants see themselves as having support or help at work or at home. Results also indicate that respondents know their coordinator and receive help from the coordinator. The number in parenthesis above each chart indicates the percentage of affirmative responses in 2008.

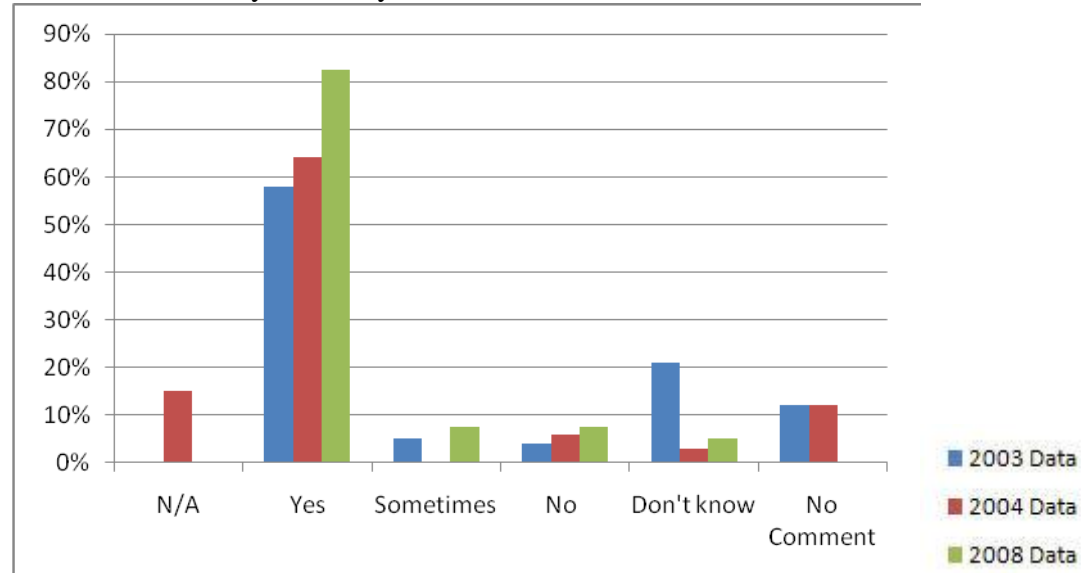
(90%)

19. Do you know your coordinator? ( Previous wording: Do you know your case manager/service coordinator?)



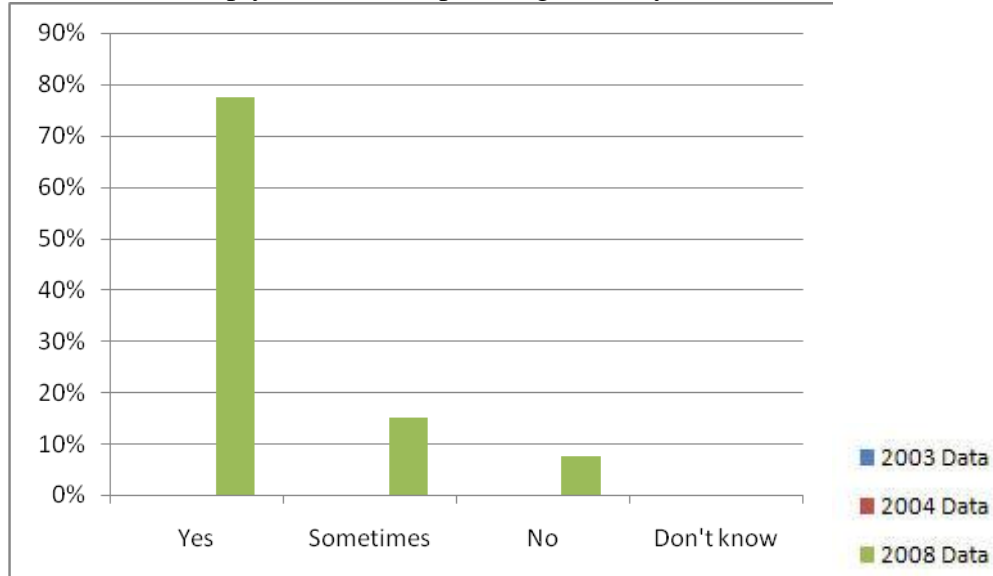
(82.5%)

21. Does s/he ask you what you want?



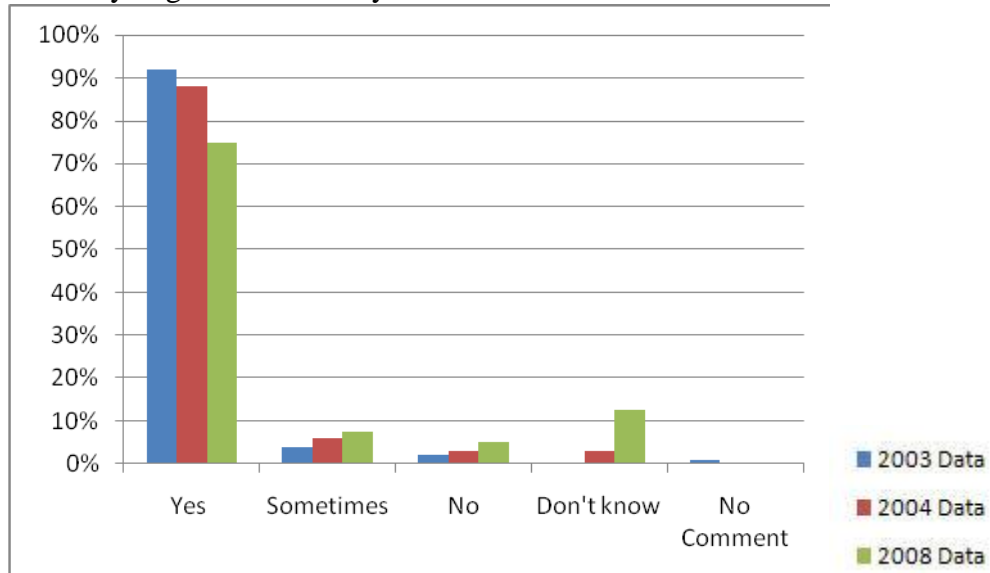
(78%)

22. Does s/he help you to make a plan to get what you want and need? (Asked only in 2008)



(75%)

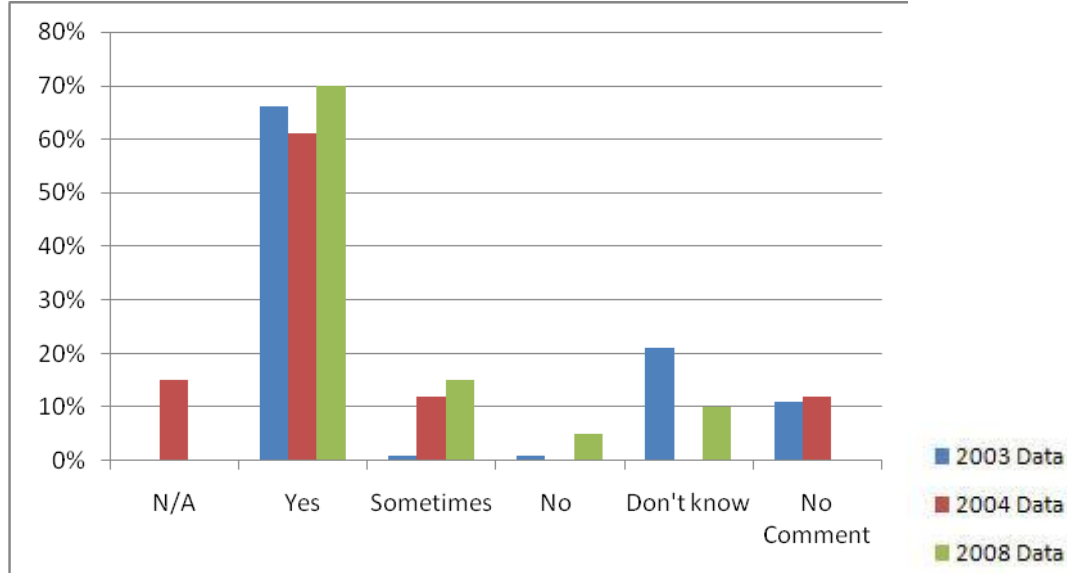
53. Do you get the services you need?





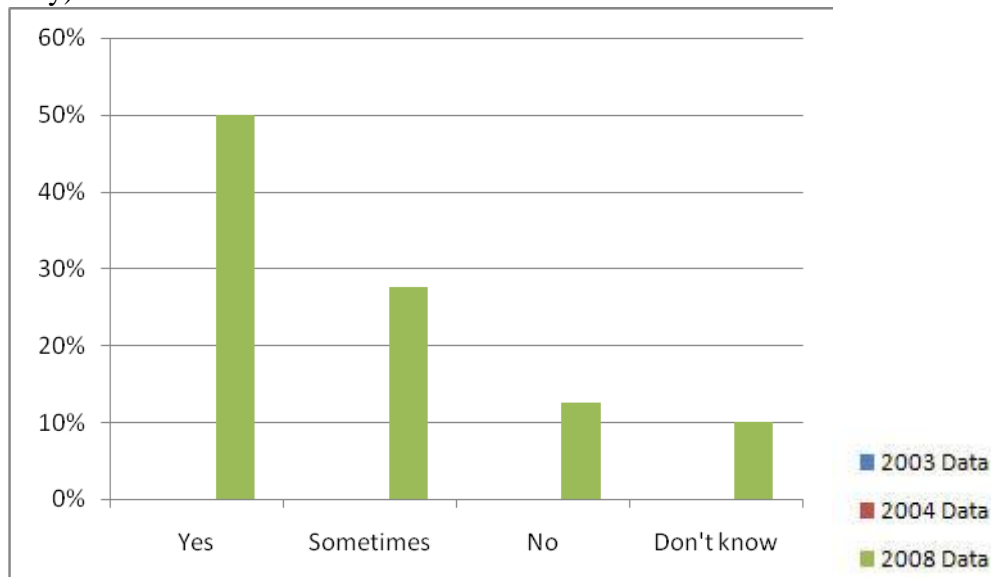
(70)

20. If you ask for something, does s/he help you get what you need?



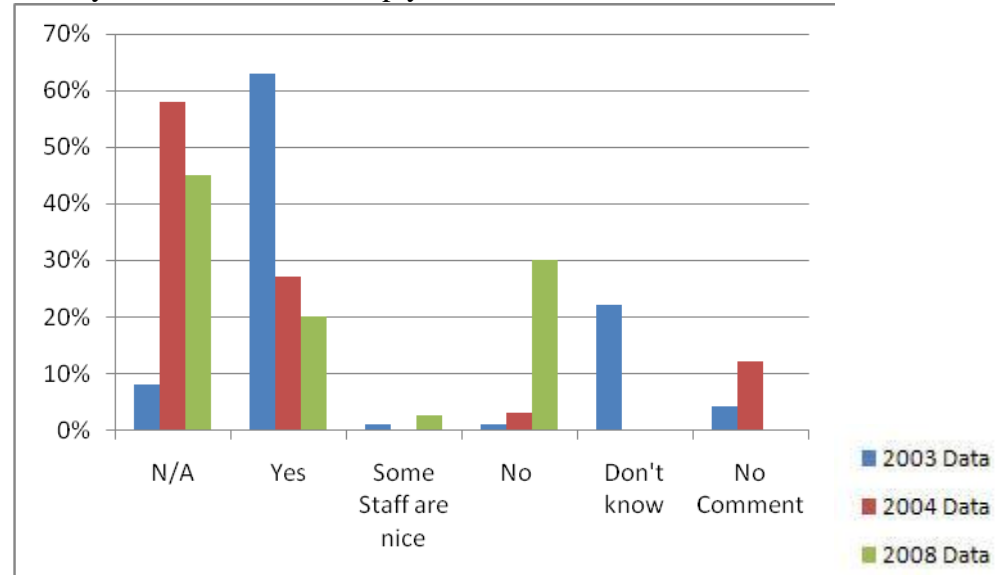
(50%)

24. Does the coordinator help you to find resources or people who can help you? (Asked in 2008 only)



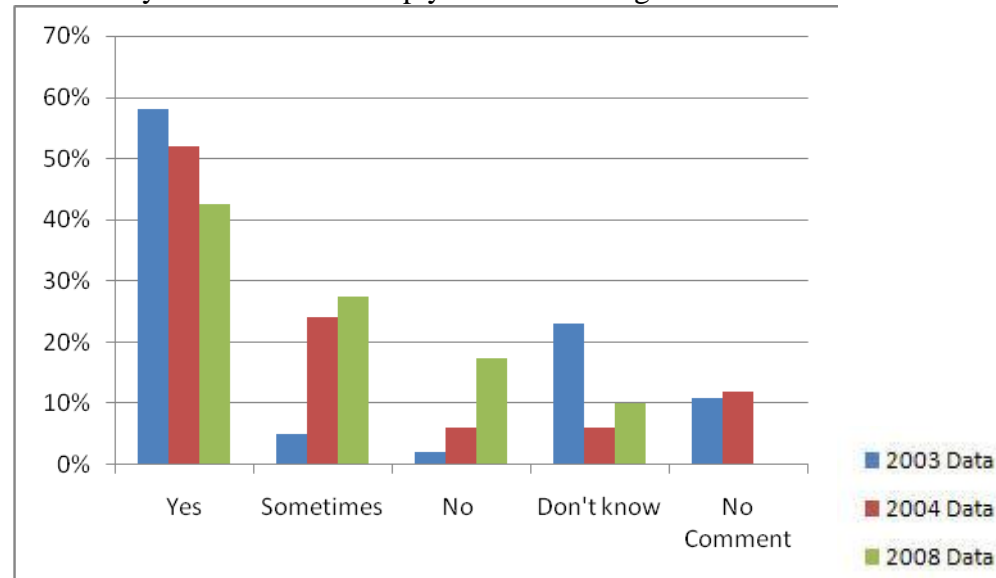
(20%)

2. Do you have staff who help you there?



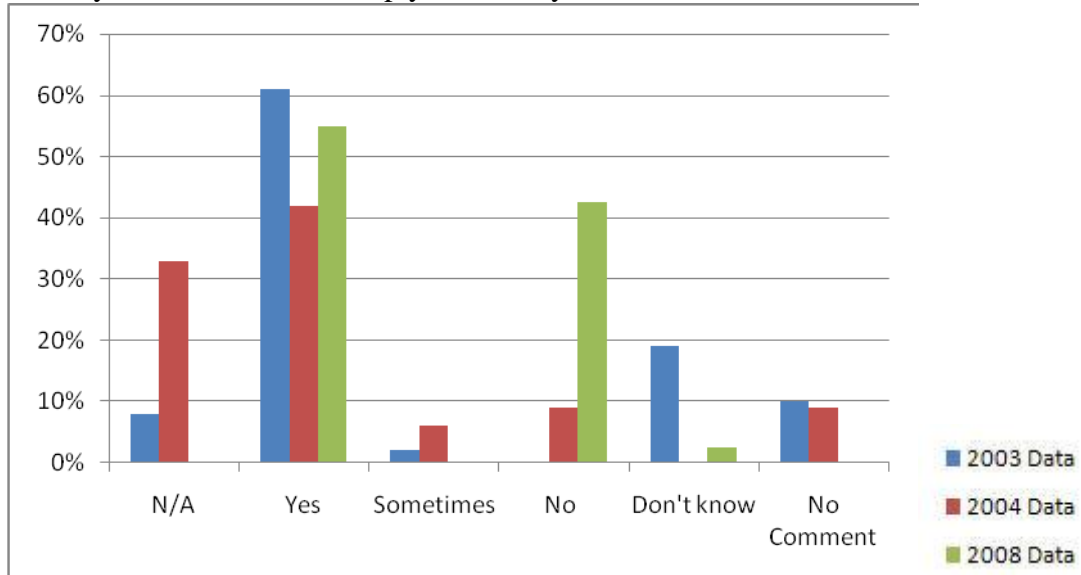
(42.5%)

23. Does your coordinator help you do new things?



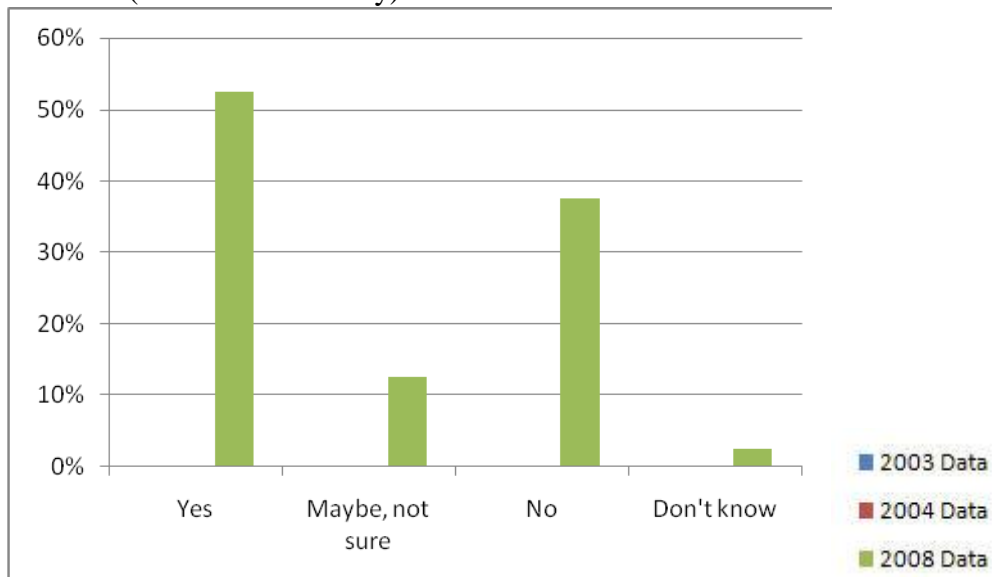
(55%)

9. Do you have staff who help you where you live?



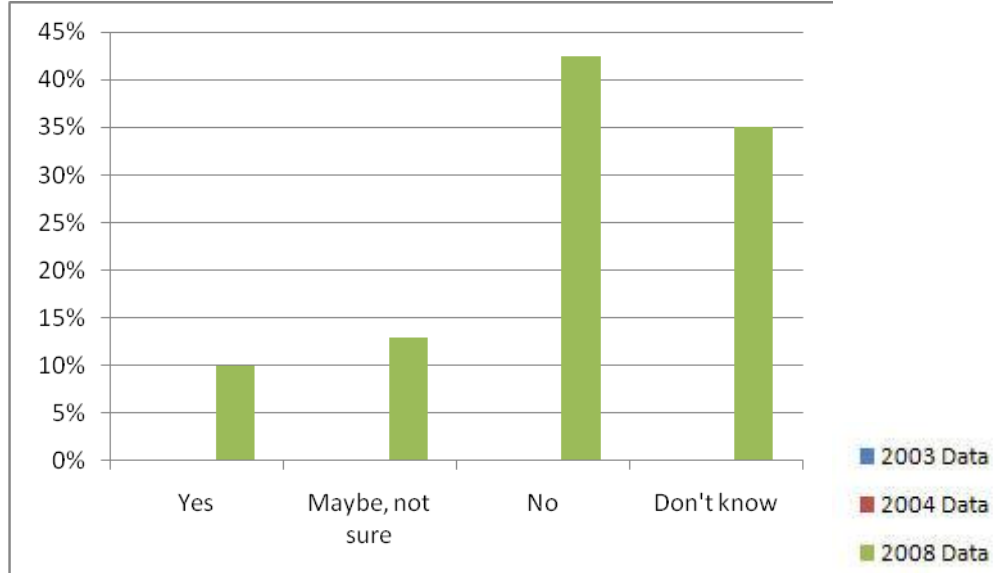
(53%)

28. When you have your annual meeting, does someone tell you how much money is in your account? (Asked in 2008 only)



(10%)

27. Do you know how much money is spent on paying for your providers? (Asked in 2008 only)



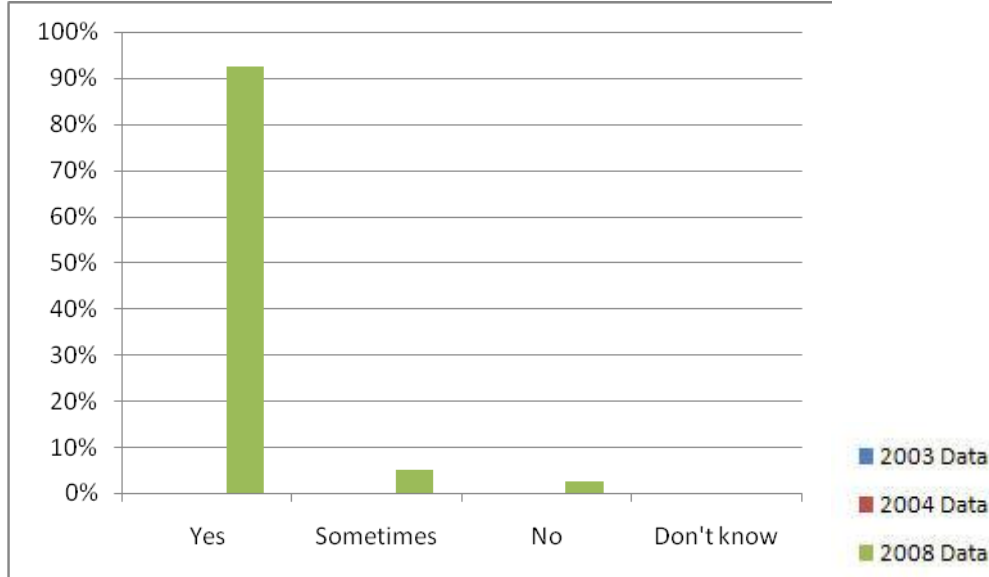
## Appendix G

### Complete results of satisfaction questions

Nine questions were targeted at general satisfaction. Seventy percent of respondents saw themselves as happy and satisfied with the services they receive. The number in parenthesis above each chart indicates the percentage of affirmative responses in 2008.

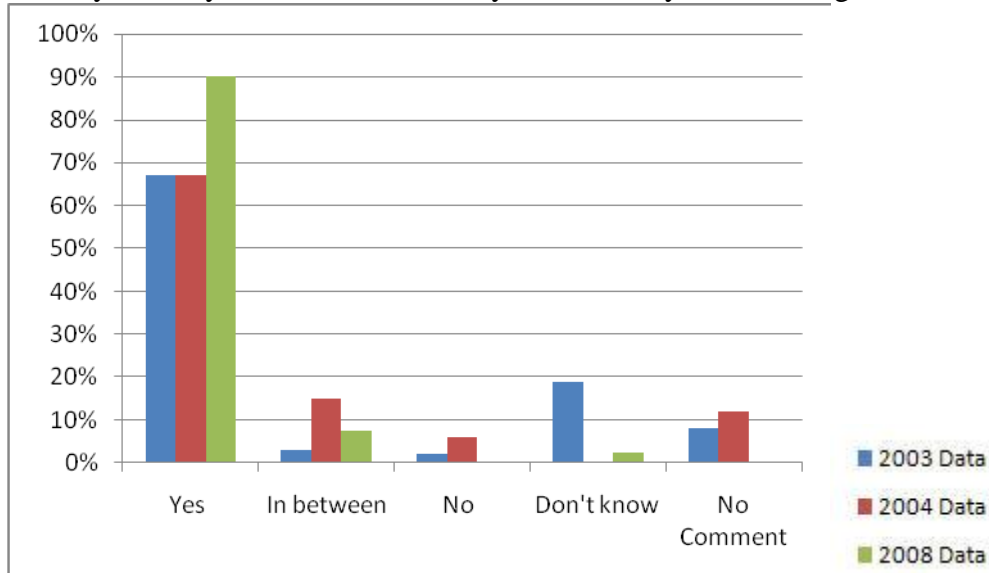
(93%)

25. Are you happy with the services that you receive from the coordinator? (Asked only in 2008)



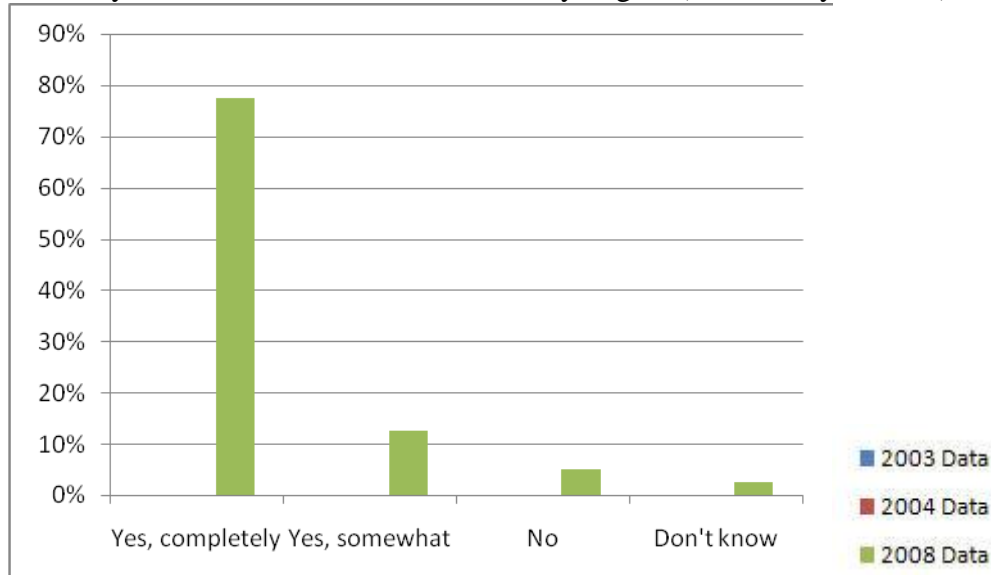
(90%)

5. Do you like your home and where you live? Do you like living here?



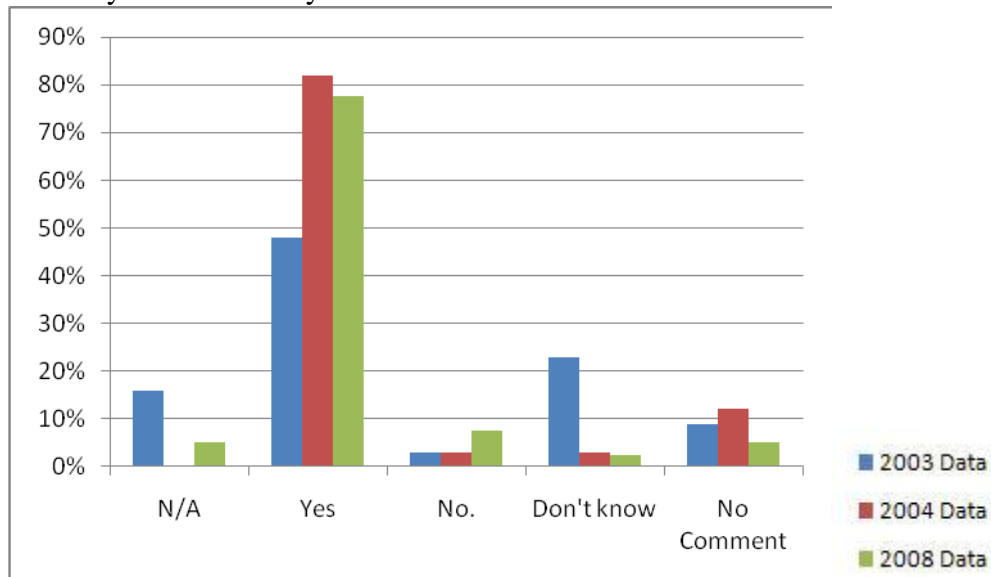
(78%)

54. Are you satisfied with the services that you get? (Asked only in 2008)



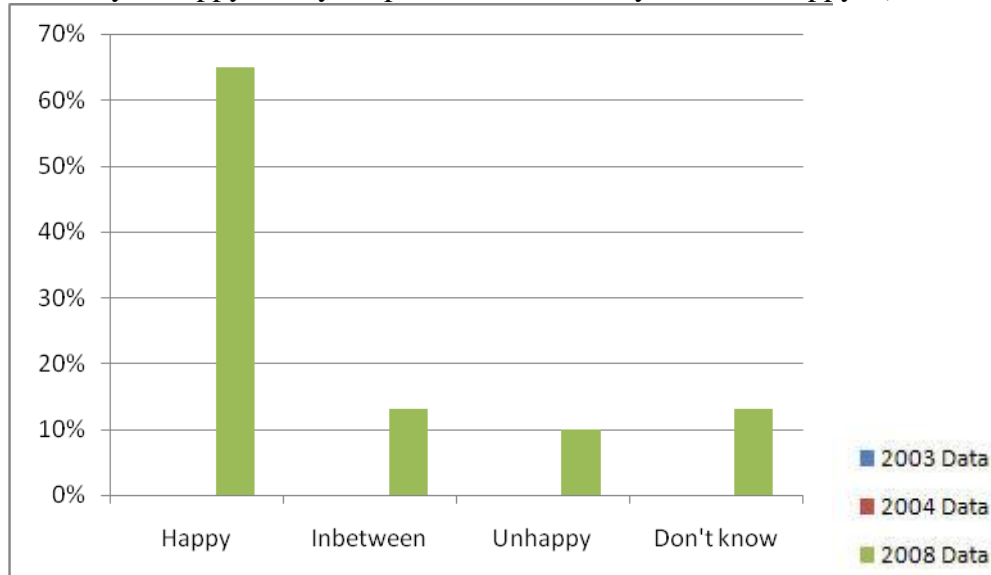
(77.5%)

6. Can you be alone if you want to?



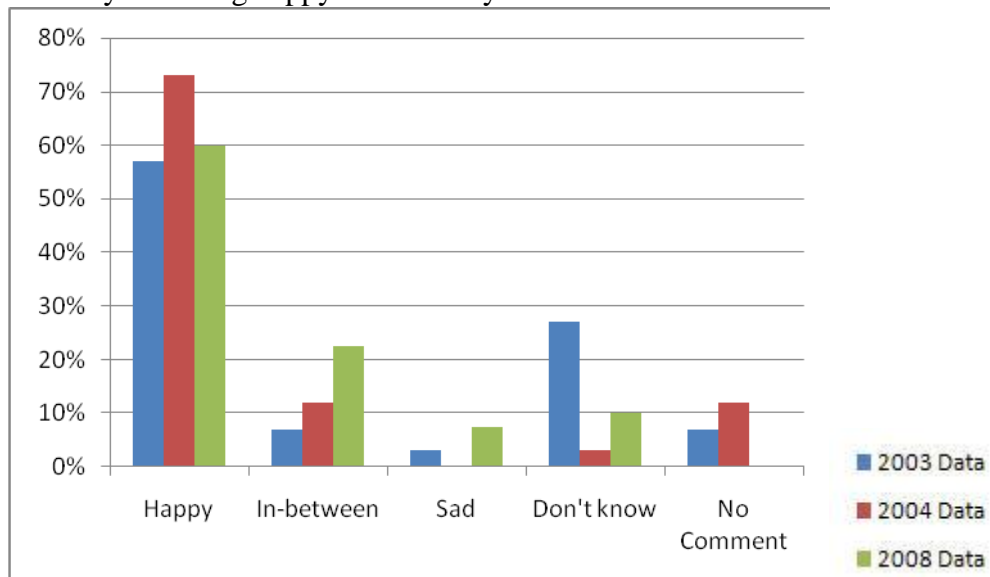
(65%)

16. Are you happy with your personal life, or do you feel unhappy? (Asked only in 2008)



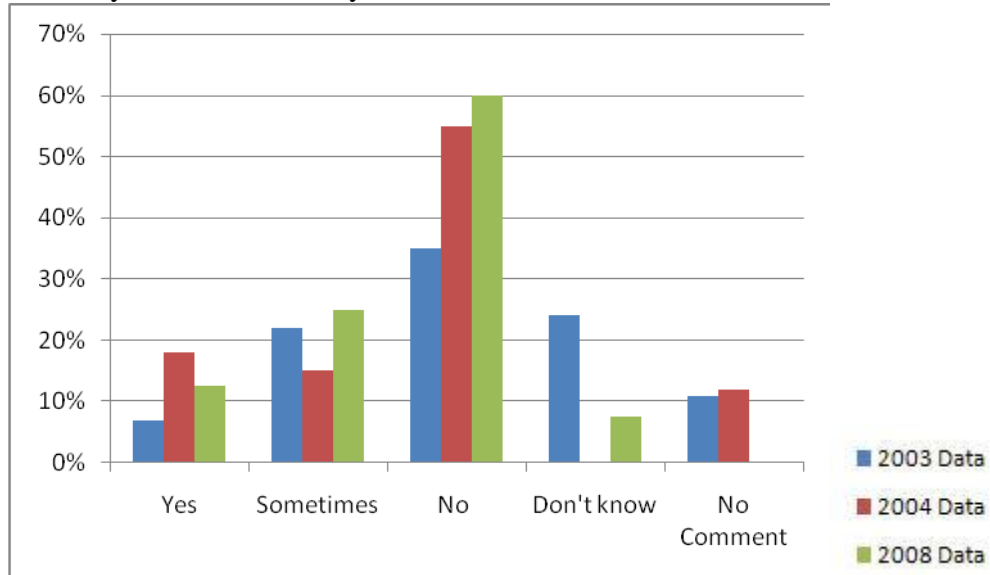
(60%)

4. Are you feeling happy or sad today?



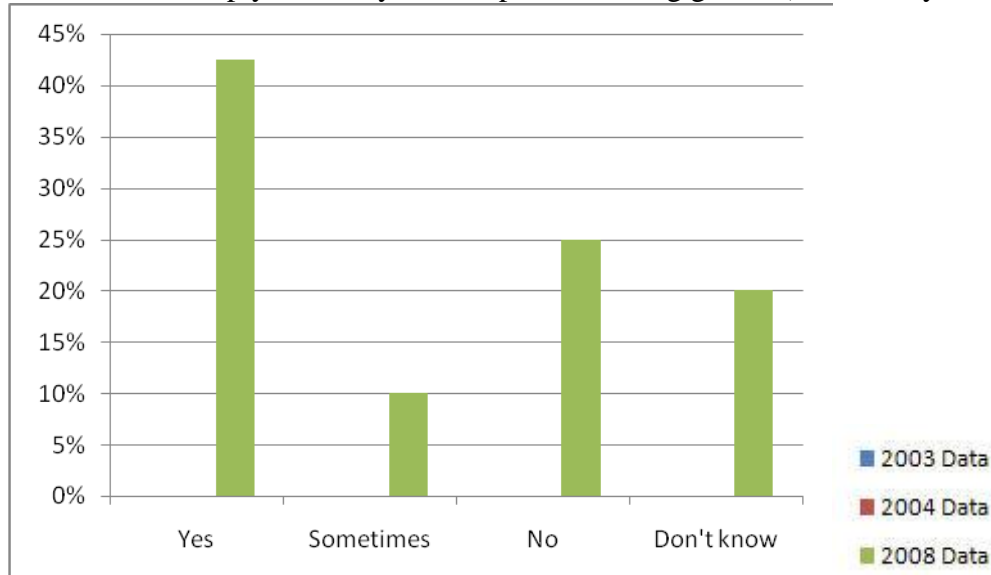
(60%)

17. Do you ever feel lonely?



(43%)

10. Does s/he help you meet your independent living goals? (Asked only in 2008)





## Appendix H

### Open comments during the interviews

#### Services needed

- Physical therapy
- Get out, get job
- Computer classes
- Handicap devices and handicap door opener
- Driver's permit
- Job
- More job help
- Transportation assistance

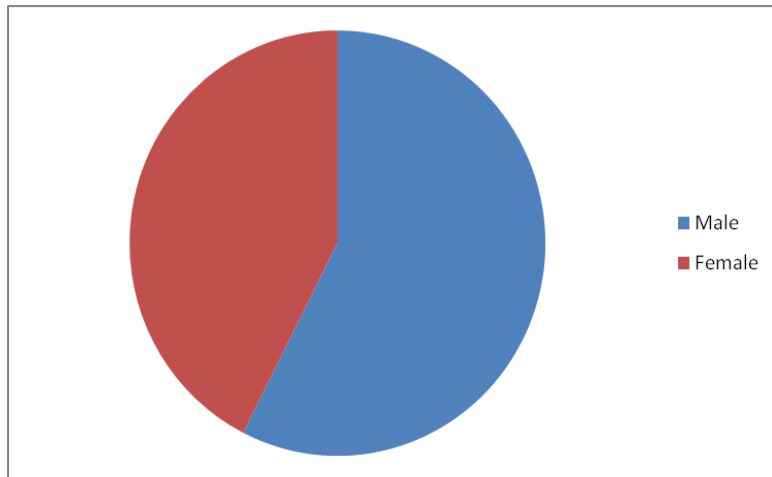
#### Service changes

- Job coach
- Build self confidence
- More time with providers
- "I would know more about what is going on."

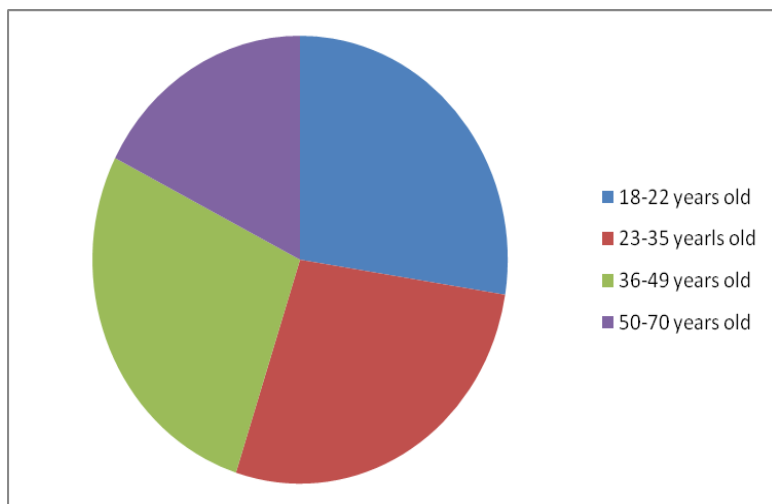
#### Information to add

- "I know how to take care of myself."
- "[The coordinator] helps me; I'm her boss."
- PLANS is the best there ever was. We don't have many services. We wish we could tell more people about PLANS
- The services are delivered at an appropriate rate and safe manner.
- After I met [the coordinator], things went south
- "[The coordinator] does an excellent job. [The coordinator] is loving, kind, understanding."
- "I am doing good by myself."
- "My child is doing well. What we want is what she wants."
- "If I keep going, I will have something."
- PLANS has been a good program.
- "I am happy the way I am living."
- Learn job one step at a time.

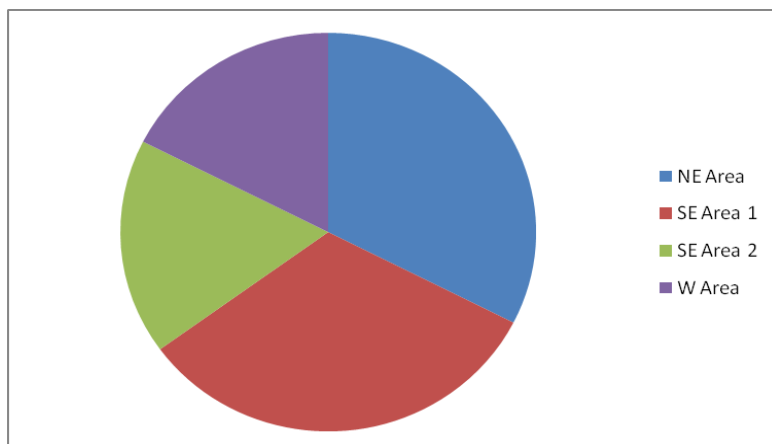
# Appendix I Demographics of 2008 respondents



23 Males  
17 Females



Eleven 18-22 year olds  
Eleven 23-35 year olds  
Eleven 36-40 year olds  
Seven 50-70 year olds



13 Northeast Area participants  
13 Southeast Area 1 participants  
7 Western Area participants  
7 Southeast Area 2 participants